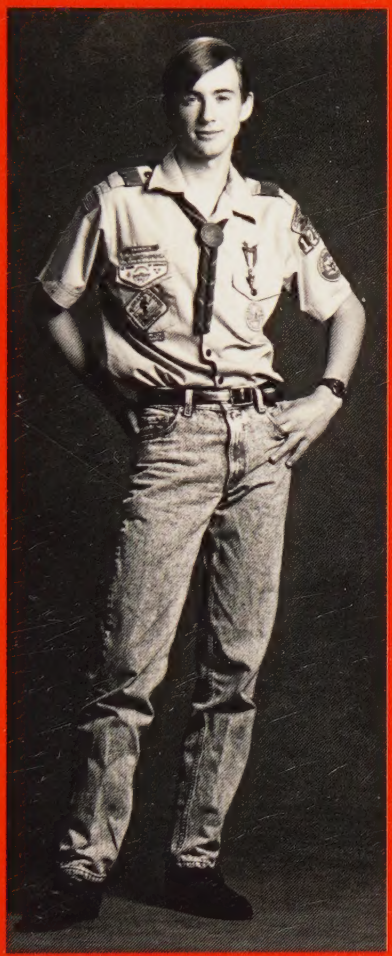

Henry for President

Please share this
copy of
Henry for President
This story is our
son's only legacy.
Thank you!
Hank &
Joan

Henry For President

Second Edition
2009

Acknowledgements:

Many people deserve thanks for the help that they gave in the evolution of this story and in the writing of this book.

Joan's and my parents, Hank and Irma Nicols and Tom and Rosemary O'Donnell were first and foremost in their unconditional support and love. Their modeled behavior gave Joan and me the foundation by which we raised our own family. We owe them more than we can say!

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Many, many more people and stories could be included in this memoir for their profound influence and effect on our lives but because of the limitations of time and space have been omitted. There were just too many stories to tell!

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To: Henry
From: Dad
Subject: The Presidential Primaries and Your Book
Date: Summer, 2008

Hey Henry,

It has been awhile since we last chatted, and I thought I would bring you up to speed. All is well here. Everyone in the family is doing fine. Your mom and sisters are still driving me crazy. Same O, same O.

The big news here is the Presidential Primaries. The Republicans are all in lock step behind their candidate (again). The Democrats have organized a circular firing squad and are still taking aim at each other. It seems like very little changes. As you predicted more than a dozen years ago, this would have been the time for you to fulfill your dream of running for President of the United States. Of course your birthday is not until August, and you won't be 35 or eligible to run until then. Trust me, if you were here now, you would be a contender!

I have finished the book. I think it is a pretty accurate telling of your story. I wish you had written it instead of me, but that was not to be. The hardest thing I ever had to do was to watch you die.

This book has been hard to write. It was hard on Joan and me as your parents trying to describe your extraordinary life and untimely death. It was hard on your sisters, Jennifer and Diana, as we all congered up the memories associated with the difficult times that we lived through.

But Henry you know that this book is important. Although the reality and the stigma of AIDS and death were a constant shadow over the story of your life, together we experienced great joy as a family. It is that bitter sweet mix of a life—the

agony and the ecstasy-- that makes the story so hard to tell but so worthwhile.

Henry, you did not need to die so young. The fear, ignorance and the silence of the times conspired to claim your life. Now that any future contribution and your potential have been denied, it is only your legacy that can survive. Your contribution to diminish the harsh discrimination of those with HIV/AIDS is a powerful legacy and that story needs to be told. How you lived your life with all the challenges you faced can inspire others to have the courage to take a stand and speak up for what is right.

That then is the point of this book. It is the legacy of a hero who helped to change the world and whose life was taken too soon. I have decided to dedicate this book, your story, to the next generation of our family; Victoria and Zach, Jennifer's children who remember their uncle. (Zach doesn't remember you very well. He was young when you died.) And to Tess, Lincoln, and Tara,--Diana's children who know you only from the stories we tell and the pictures we show. I want them all to know the whole story of their Uncle Henry, as best I can tell it, as best I remember it.

All my love,
Dad

PS: But Henry, your story does not start with you or with AIDS, it starts with Joan and me.

Joan and Me

Joan and I have been married forever, or maybe it just seems like forever. But then, sometimes it seems like we only met just yesterday. I can still remember the first time I saw her. It was September 11, 1967, at about 7 P.M. We had both finished the first day of freshman orientation, and we were walking down a steep grassy hill on the "cow path." It was a short cut used by the students at the State University College at Oneonta (S.U.C.O.) to get from campus to town. Town was where the bars were. Bars were where college students went after school or, as in our case, after freshman orientation. In those days, eighteen years was old enough to drink in New York State. In our little college town, drinking was about the only thing to do. S.U.C.O. was known far and wide among college students as party town, USA, with more bars per capita there than in anywhere else in the civilized world.

We had both been at college for only a few hours, having been dropped off by our respective parents that afternoon. It was the first time that I was truly away from home and on my own. I was walking with my roommates, Ken and Al. Together, we were going to scope out the town, check out the bars, and go looking for girls.

Joan was walking with her friends, Heidi, Laura, and Sue. Ken, my roommate, knew Heidi, Joan's roommate, from his days in high school on Long Island, about two hundred miles to the south. Their group of four and our group of three decided to explore the city, our new home, together. As nearly as I could tell, the girls were looking for guys. Well, it was the thing to do.

Joan was wearing pumpkin orange colored "hip huggers." They were a style of girls' jeans that conformed very well to the female frame, thus the name. They fit her well. She also wore an earthy colored, paisley, long sleeved polyester shirt. On her feet, sandals made from buffalo hide. The sandals were open-toed, with a single toe strap. They didn't provide her much

support as she walked awkwardly down the steep path coming down the hill. Joan's hair was a deep auburn red. Her face was spotted with the perfect number of freckles befitting such a cute girl of Irish descent. Joan's glasses were deep brown, nearly the same color as her hair. The glasses were slightly angular, but not like those sharply angled cat's eye glasses that had been popular years earlier. I knew as soon as we spoke that I liked her. She asked me lots of questions, mostly questions about me.

We talked that night about our hopes, our plans and our futures. My major was political science. Joan wanted to be a fashion designer. Her major was home economics. We never made it to the bars that night. Joan and I had such a good time visiting and talking that we discovered that we mostly wanted to be together. We left the others when we got to the streets with the bars. Instead we walked all over the city that night. It took us less than six weeks to decide that we would spend the rest of our lives together, making babies, raising our family, and sharing the best and the very worst of what life could possibly give to anyone.

Neither of us could have known on that cool, gentle, wonderful September evening when we first met that together we would set in motion a chain of events that would have a profound effect, not just on us, and not just on our children to come, but on the lives of thousands of others who would be touched by our joys and our tears, by the story of our lives and by the story of our family.

Together, we experienced the joys hoped for by every couple and the sorrows feared by every couple. This is our story. This is the time to tell it.

Joan and I spent most of our first few months together getting to know each other, our respective families and our histories.

I am Hank, the oldest of five brothers. I was the firstborn to Henry R. Nicols and Irma Barth Nicols. My father was a New York City fireman. My mother was a German war bride who

emigrated from Germany shortly after the Second World War to marry one of her country's occupying soldiers, my dad. Her parents (my grandparents, Grossmutter and Grossvatter Barth) encouraged their daughter Irma to leave her family and her country to travel to a distant and unknown land to marry her boyfriend (my father). They understood that she would have a better life in America. They wanted what was best for their daughter. Parents want what is best for their children. Joan and I wanted what was best for our children, too. We just weren't able to always have it.

Joan's parents were middle class working folk of Irish descent. Joan's father, Thomas O'Donnell, married his girlfriend, Rosemary Herzog, when he returned from serving in the U.S. Marine Corps in the South Pacific in the Second World War. Tom and Rosemary had seven children—four girls and three boys. Joan was the second of the seven.

With Joan and me and later with our brothers and our sisters, went the dreams and the hopes of our parents, our grand parents, and untold generations before. So it is with children, the future lies in their lives. The hope for tomorrow and the plan for eternity lie in the present lives of our children. Children are our ultimate legacy. When we are gone, our hope is that we will live on in the memories and the love of those generations yet to come. Our children link us to immortality.

Joan and I married against her parents' wishes but with their blessing as we began our second year in college.
They were concerned that we should finish school before taking on the added responsibilities of marriage and a family. We didn't listen. We both continued in college as married students until the summer between our sophomore and junior years when Joan dropped out of school to have our first child.

1. Hank and Joan November 3, 1968

We were both just nineteen years old when our first child was born. We were children having children, but boy, were we good at it!

Our Children

The days of being a carefree, college student ended when we married as my responsibilities extended to more than my studies. To support us I worked full time in a gas station. We rented an apartment in a house at 30 Maple Street. The apartment was walking distance to the campus—a good thing because we had no car. We walked everywhere-- to school and even to work. But I loved being married, and if it were possible, I loved being a father even more.

Jennifer, our first child, was born on June 18, 1969. Joan and I had been together less than two years, but already our lives were beginning to bear the fruit of our union. Our beautiful redheaded daughter was more than enough proof - as if we needed any proof at all.

After the baby was born, our lives settled into as much routine as self-sufficient, married college students could have had. I continued to work full time at the East End Texaco, a 24 hour gas station. I also worked part time as a projectionist for the college union, showing movies on the weekend in the days when movies were real and came on reels. I learned a lot about movies and about being a projectionist. I learned to watch for reel changes, the secret symbols in movies alerting the projectionist to be ready to start the second projector so that the audience can have a seamless viewing experience. I guess that reel changes are history today, in the age of digital everything. I suspect projectionists are already or are soon to be an extinct breed as well.

Working two jobs, having a wife and a baby, and attending school made it necessary to buy a car. Joan worked as a waitress in either a local doughnut shop and then in Diana's, a Greek restaurant on the Main Street in Oneonta. Joan's employment depended on the season and the varying need for waitresses. We saw each other occasionally as we passed Jennifer back and forth between our respective jobs and my going to school. On more than one occasion Jennifer helped

me work the night shift at the East End Texaco station by sleeping peacefully in the back of our 1960 Ford Falcon in a crib fashioned in the back seat. More often, Jena did not sleep and wanted to play all night. Sometimes, I would deliberately keep our baby daughter up all night so that all three of us could sleep for a few hours in the morning before classes began. It was a great life!

In late 1969, Joan and I realized that employment opportunities for political scientists graduating from the State University College were scarce. The ongoing Viet Nam war was becoming more and more unpopular. Protests were occurring more frequently. Politicians like Lyndon Johnson, who had been one of my heroes, were being cast aside, discarded and unappreciated. It was a strange time for our country, and it was an unsettling time for us. For the first time in our lives we were forced to consider pragmatic alternatives, not from a hypothetical or argumentative position, but from the position of reality. There were bills to pay and mouths to feed. Soon college would be over, and we would begin the business of life as adults.

In order to support my family as best I could, I became an education major. It did not exactly have the same "sex appeal" as being a political scientist, but I could think of no better way to contribute to the future than to help teach those who would be the future. Joan and I revamped my political science course transcript and reworked my resume. With a little fancy footwork and a few additional education courses, I was ready to graduate in the spring of 1971. Joan was pregnant again, and I was student teaching.

I was a great student teacher and knew I would be a great teacher. I loved teaching, so the transition was easy. I earned my teaching certification in May. That was when we discovered that teachers were a dime a dozen and teaching positions were nearly impossible to find.

After completing student teaching, I accepted a summer position as the waterfront director and head lifeguard at the Boy Scout camp where I had gone as a Scout. As the waterfront

director, I had a staff of six other lifeguards and counselors. I spent the summer working and playing on a beautiful lake, teaching Scouts swimming and canoeing. I guided them in their quest for the coveted lifesaving merit badge.

Although the summer was filled with good times, the meager job market still haunted our thoughts. By the end of the summer of 1971, we were unable to find anything but long lines at the interview sites. As a final concession to reality, with the knowledge that Joan was having another baby in November, I accepted a job as a professional Boy Scout Executive in Binghamton, New York. Although I loved scouting and was an Eagle Scout, I wanted to be a teacher. My problem was that no one wanted me. I was gratified at being accepted as an adult Boy Scout and pleased by the knowledge that this job would allow me to support my growing family. I did feel personally rejected by my would-be chosen profession. But a job is a job, and I thought I needed to accept that for now. In late August we returned to the college recruitment office to remove my name from the job seekers list. Much to our surprise and my pleasure, we found an immediate, but temporary opening to fill a vacancy caused by a woman on maternity leave in Middleburgh, NY.

Middleburgh was the same rural school district where I had student taught just six months before. As I said previously, I had been a great student teacher. Surely they would remember me. Surely someone there would recommend me. Surely my local experience would be considered well by the board in making the hiring decision. A phone call to the school revealed that the Board of Education was meeting that night to make a decision. They were considering several other candidates and if I wanted to be interviewed, I would need to drive the fifty miles from Oneonta to Middleburgh immediately. Joan and I packed Jennifer into the car and took off. Three hours later the interview was over, and the position was mine—a full-time position teaching high school and junior high school social studies and history. What could be more perfect? I was to be paid a competitive wage of $7,200 for the year.

Even though the position could be guaranteed for only one year, we felt great. Joan and I could now begin the business of life in earnest. With one daughter in hand and another child only a few months away, we rented a small one-bedroom apartment. It was over the Elm Store, a local five and dime business that predated Woolworth's but looked like a Woolworth's general store. The Elm Store sold dry goods, hardware, clothing, and shoes. You could find just about everything you could want or need to live in Middleburgh. The store closed at 5:00 P.M. weekdays and at 2:00 P.M. on Saturdays. We considered the location perfect for us. Life was getting better and better (if that were possible).

As fine a student teacher as I had been, I was better as a real teacher. No longer did I have a master teacher nurturing my development. I was finally on my own with my classes and, boy, were we good together! I quickly became a talented and popular teacher. My colleague, Dan Larkin shared the limelight with me. Dan also taught social studies, and the two of us led the free-thinking, political discussions in the smoke-filled, coffee-stained, crowded faculty room. We would have solved many of the great issues of the day if only anyone had listened to our counsel. With our other colleagues, we oversaw the end of the Viet Nam war, the prison riots and deaths in Attica, NY, the rise and fall of George McGovern, and the other historic events of the early 1970's.

But all of that was dwarfed in significance by the most important event of 1971. On November 14th, I was sitting in the waiting room in Cobleskill General Hospital, marking papers. Jennifer was visiting her grandparents in Catskill, NY, some sixty miles away when Joan delivered our second child, Diana. She was another redhead, like her mother and sister. I was seriously outnumbered by redheaded females. I should have known then that there was going to be trouble! Then during my first year of professional employment, a plan began to evolve. It occurred to me that as a teacher in New York State, I would only teach school for 183 days a year. I would need a little more time for preparation and other school responsibilities, but considerable time would be available during summer vacation for me to tip the odds back in my favor. Three to one

(redheaded females to males) was not fair, but if we were at Boy Scout camp for every summer vacation, the balance of power could be restored. The odds could be tipped back to where they should be (with me not being outnumbered).

To help even the score, I volunteered as the Scoutmaster of Boy Scout Troop 2. In addition, Joan and I became advisors to a co-ed Scout group of Explorers, which was attached to the ambulance corps where we both volunteered as Emergency Medical Technicians. My logic and my plan were inescapable. Joan, Jennifer, Diana and I were all becoming Boy Scouts.

The year of 1972 went exactly according to plan. In fact, it was better. Jodi (the teacher on maternity leave) decided that she liked being a full time mother, which left her teaching job to me. The Boy Scout camp needed a Director of Aquatics. There were now 18 lifeguards to supervise and three waterfronts. Our little family was settling into the good life. We had enough money to pay most of the bills most of the time. We spent summers in the Catskill Mountains in a cabin on a lake in the woods. We spent a lot of our time together, as much as a young family could want.

We even had enough money that we could indulge in occasional extravagances. We taught Jennifer that we were living in affluence. But we changed the meaning of "living in affluence". On payday, when we had a few extra dollars, we would "live in affluence". It meant we would stop and buy fast food French fries as a treat.

Once in front of my parents Jennifer innocently asked, "Could we live in affluence today?" My parents were surprised that a less than three-year-old could ask such a question until I explained that affluence meant, "May I have French fries?"

That same year we had a little bit of extra money, and I had always wanted to sky dive. Right before the summer camp season opened up, I was able to convince my open-minded wife and my two daughters that this extravagance was necessary to

complete my wish list of life's opportunities. So, when school was out and before camp came into session, we all ventured together to Bloomingburg, New York, to the nearest skydiving school. Joan had her doubts. The kids were much too small to participate meaningfully, but they all came along to support my decision and watch my hoped-for successful jump.

After a day long, personal one-on-one class about the intricacies of sky diving, the time came for my first jump. It would be a static line jump, meaning that the parachute would be opened by a line attached to my back. There was only about 30' of freefall. It was so simple even a beginning jumper could do it. I quickly found out that it was not that easy. My landing was terrible. Oh, the parachute worked fine. I came in to the airport target zone exactly as directed by the ground crew, but when I landed, I was so pleased with myself that I forgot to roll. I landed standing up. I heard a crack inside my knee and ankle and knew it was bad. An orthopedic surgeon would later remove my shattered right knee cartilage, but the immediate pain was from my badly sprained ankle.

The other more experienced jumpers landed shortly after I did. They all congratulated me on my first jump. My jumpmaster, Al King, told me it was the worst exit from a plane and the worst landing he had ever seen. But, in skydiving as in flying, any jump you walk away from is a good jump. I think Al, the jumpmaster, was just jealous that I landed closer to the target than anyone else in our group, even closer than Al. That was my first and, to this day, my last jump. But, then I am still young, perhaps tomorrow?

When we left the airport I insisted on driving away. I lied about the pain in my ankle so the other jumpers would not know how badly I was injured. Joan loaded the children into the back seat as I received final congratulations and pats on the back from my newfound, high-flying friends. Once outside the airport, Joan drove. My foot hurt way too much for me to keep up the pretence in front of my wife and young daughters.

The summer of 1972 was spent hobbling around the camp with a cane, and by September I was ready to get back to

teaching. The year went by much like the preceding one, but now, with a year of experience under my chalk, I was more than a chapter ahead of the kids. I went from being a great teacher to being one of the very best. I loved my job, and the students enjoyed my classes. I had fewer absences and more participation than my colleagues who complained of discipline problems a lot more than I did. All was right in my teaching world. In December, I had the damage I had done to my knee repaired and spent a long time recovering. It was about that time that Joan got pregnant with our third and final child scheduled to be born in August, 1973 when we would be back at Scout camp.

Joan and I discussed her having our soon-to-be-born new addition. As was the custom of the times, I had been excluded from the delivery room at the birth of both of my daughters. There was some common belief among physicians that, although fathers were necessary to start the conception process, they were not only unnecessary but undesired at the delivery. Joan and I talked about it a lot. Contrary to the idea that men might faint dead away at the sight of childbirth, we thought that my ambulance training and experience working at serious car accidents as an Emergency Medical Technician prepared me well enough to handle the experience of childbirth. The issue however, was not with us. The issue was the healthcare community. Doctors believed that Dads did not belong in the delivery room!

Joan and I called every doctor near our summer camp. Finally, after more than fifteen calls, we found a physician who would agree to allow me to be present for the birth of our child. The doctor was located in Monticello, New York, about thirty miles away. He assured us that he would be pleased to allow fatherly participation at more than conception. We won. Joan and I wanted this child to be born naturally, with little anesthesia. We wanted to be fully present to both witness and welcome the newest family member.

Joan had proven during the birth of our first two babies to be a patient and, if anything, slow deliverer. Unusually long labor times and giving birth to large babies seemed to be the norm for her. Both Jena and Diana were more than eight pounds. There was no reason to believe that number three would be any different. But when Joan went into labor, we raced to the hospital nevertheless. Once safely surrounded by all sorts of folks in white at the hospital, we relaxed, and so did the baby. Joan waited patiently as did the baby, who was apparently unsure of when its birthday should be.

We waited, and waited, and waited. Finally, after visiting with the staff, telling and hearing lots of stories, and more than two days in labor, the time had come. With the physician explaining the birthing process to me from a technical, anatomical and medical standpoint, Joan and the nurses did the work to deliver our child.

The third time was different. This time we had a boy. Like his dad, he did not have red hair and like his dad, he was outnumbered by redheaded females. But now at least the score was evened a little at three redheaded women to two outclassed blond males! As soon as Henry, our son was delivered, the doctor took him from the nurse and wiped his little bloody foot on Joan's nose so she could see her first and only son. She cried, and so did I as I leaned over the hospital bed to kiss my wife. We had wanted a boy, but we had selected names for both a boy and a girl, considering the role of luck. We kissed again.

"Hey, I thought this was going to be your last child! That is what got you here in the first place!" Scolded the doctor. Joan and I kissed again. We would risk it!

Henry Joseph Nicols was named for his grandfather, who had been named for his father. If we were counting, Henry would have been the IVth. His middle name came from Joan's maternal grandfather, Joseph Herzog. As we had done with his two sisters before him, Joan and I carefully counted the fingers, toes, eyes, ears and nose of our first and only son. Thankfully,

he had exactly the right number. Like his sisters before him, he was perfect. Our lives seemed perfect.

After the requisite time in the hospital, Joan returned to our summer home in the woods on the lake at Onteora Scout Reservation. Onteora is a Native American, Indian word that means "Land in the Sky." Onteora was indeed the "Land in the Sky." Onteora is in the Catskill Mountains about two hundred miles from Long Island. The camp comprises thousands of acres of land that had been wisely purchased in the 1950's by Nassau County. Long Island Council, B.S.A. Each year more than a thousand Metropolitan Scouts spent two weeks of their summer learning to hike, swim, canoe, fish, cook, camp and enjoy nature in the "Land in the Sky." The only people who enjoyed the camp more than the Scouts were the 120 staff members who worked and played over the 10 week camp season.

We love Onteora and the friends we made there. Spending ten weeks over several years in very close proximity working, living and playing together we developed lifelong, close friendships.

So it was with Henry's godparents. When the time came for his christening, Joan and I asked Joe and Delores Grupp to be Henry's godparents. Joe and Delores were staff members like us and had lots in common with us. Joe was a teacher from Long Island and Delores worked in the health lodge with Joan where the children of the camp came to have their injuries and wounds nursed back to health.

Henry's christening was "THE" event of the season. A chapel in the woods would be the setting for this special occasion. Both Joan's and my families were joined by most of the one hundred twenty staff members in the camp for the first ever known christening in a Boy Scout camp. Father Bob, the Roman Catholic priest and camp chaplain, welcomed Henry into the Catholic faith surrounded by squirrels and birds and a host of other creatures.

This was what life should be like! It was the end of the summer of 1973, and all was well. In fact, it probably couldn't have been much better. We were together with our small but now complete family of five, surrounded by our larger family, our friends and nature in the greatest of God's churches, the woods of the Catskill Mountains. Life had been good to us.

The summer ended quickly after Henry's christening and, before it seemed possible, we were back in Middleburgh. Joan again worked part time as a waitress and I returned to teaching. We shared the parenting of our three children. Jena was four, Diana was two, and Henry was a newborn. There was a lot of parenting to share.

School seemed different. It took me a while to figure out what it was, but I did. I was still teaching the same courses; I had many of the same students. Only the 7th graders were new as I had taught the now 8th and 9th grade classes in previous years. My classroom was the same; the books were the same; my friends were the same; everything was exactly the same. Then like a stroke of genius, like a flash of lightening, like a huge crashing sound of a symbol, I realized what was different. It was me. I was bored.

Just about that time, I got a letter from the United States Army. It said something like....

"Dear College Graduate; Are you really happy with what you are doing?"

I wasn't. The U.S. Army offered to change my life.

The US Army

It was the spring of 1974. Three years of teaching were enough. I was too young to teach. With Joan supporting my decision, I enlisted in the Army. At that time the Viet Nam War was winding down. The Army was short on educated and trained individuals so the government initiated a program called "Stripes for Skills." My college degree qualified me for both Officer Candidate School and the opportunity to get an early start on a career in a new field. As I looked down the skills that the Army thought I had, I saw "Police Investigator." Now, that sounded interesting! I could enlist in the Army and become a Spec IV (Corporal) and not only choose my career field but I could select my location. Joan and I talked about it. We thought it might be a good way for our young family to travel and give me a new career as well. We agreed that I would enlist in Army for the military police school in Fort Gordon, Georgia. After advanced training and with a little bit of experience as a military police officer, I would become an investigator. Then, we would go to Germany, (Where my mother's family still lived.) We could explore Europe at the expense of Uncle Sam!

It was a brilliant plan. In September of 1974, I would leave for basic training. Joan and I planned to spend one more summer working at the Scout camp, and then we would start our next adventure.

Just before I was to leave for the Army, two things happened that would foreshadow what was to be. Jennifer was admitted to the local hospital near the camp with severe, unexplained gastrointestinal bleeding. She was both vomiting blood and excreting blood. Bleeding from both ends is always a bad thing. She was quickly transferred to the larger hospital in Monticello, and then to a still larger hospital in New York City. At Colombia Presbyterian Medical Center's Babies Hospital, Jennifer was given a transfusion because she had lost so much blood. After several days in the intensive care unit, Jennifer was discharged without any definitive cause being

identified. The doctors suggested that it might have been an allergic reaction to some berries she had eaten. We didn't know when we took her home that the cause was more basic.

Later that same summer, on a weekend off, Joan and I took the children to visit the Statue of Liberty. As we boarded the ferry to cross the harbor to the Statue, Henry, who was just a toddler, fell and cut his lip. It was not a big cut. Although the cut did not bleed profusely, it bled persistently. Henry bled all the way to the Statue. Then, he bled as we climbed the stairs of the Statue to the crown and continued to bleed all the way down. By now our diaper bag was full of bloody diapers turned into compresses. There was so much blood that people were staring at us. He looked terrible. We were frightened.

We left the Statue and headed to a nearby emergency room. There the doctor said that Henry had cut a small artery in his gum behind the lip and would need a suture to stop the bleeding. Over Henry's struggling objections and cries, we held down our son as the doctor sutured the small cut. The bleeding then slowed enough that we could go home. Over the next several days, the cut behind Henry's lip continued to ooze blood. There was a large swelling behind the cut. It looked like he had been punched in the mouth. Within ten days the cut had healed, and we thought no more about it, for a while.

The summer lingered as September came to end our final summer adventure at Boy Scout camp. I left my wife and children with my in-laws and began basic training at beautiful downtown Fort Dix, New Jersey. My philosophy was not to take basic training seriously. I actually thought that my Boy Scouts were more adult than the soldiers in charge of us. I liked basic training. The eight weeks flew by. I earned the award and distinction of being the honor graduate of my unit. It was November. Joan and I and the three kids all packed into our car with a little pull- behind-trailer containing all of our worldly possessions. We were on our way to our next adventure, Fort Gordon, Georgia.

We liked Augusta. Winters were milder than what we were used to in upstate New York. The people and the army seemed

hospitable enough. We lived near the post in a trailer park of military families. Joan and the kids made friends easily and quickly. We were settling into our new lives as planned. Then the bleeding problems from the previous summer resurfaced.

Henry was playing and running, as toddlers do, when he slipped and fell and cut his chin. It wasn't much of a cut, half an inch long and very shallow. It was really too small to suture. We taped it. The next day it was still bleeding. A week later it was still oozing.

We brought our eighteen-month-old toddler to the Dwight David Eisenhower Army Medical Center where the nurses and doctors explained to us that the cut was too small to suture. They attributed the bleeding to teething. The drool and saliva from his mouth were washing away the clot before it had a chance to stop the bleeding. They would tape the cut and place a bandage over it. That should have stopped the bleeding.

The next day we returned to the clinic with his cut still bleeding. Well if plan "A" didn't work, it was time for plan "B". They would suture the cut. For the second time in his short life, we held our son down while an unhearing but sympathetic medical staff sutured a cut on his face.

Two days later we were back at the Medical Center, with a child who now had a huge swelling under the stitches. Dr. Roberts, the senior officer and physician, suggested that we might need to do some blood work to find answers about what was going on. He ordered tests including one that examined clotting issues. It should have taken seconds to have his blood clot. The test was stopped at five minutes. Henry had a prolonged clotting time. Dr. Roberts then came in to talk to Joan and me. He told us that he had made an appointment for us at the Medical College of Georgia in Augusta. We were to be seen immediately by a hematologist who specialized in bleeding disorders. Dr. Roberts was concerned that this

bleeding could be symptomatic or indicative of something more serious, like leukemia or Hemophilia.

Joan and I followed the careful directions to MCG and to the offices of Doctor Christine Johnson, M.D. Her waiting area, office, and work area were set up more like a children's play room than a medical exam room. There were toys and a wooden rocking horse. As Henry busied himself with the new toys, Joan and I were concerned about the occasional drops of blood splashing from his still bleeding chin onto the bib we put on him to soak up the blood.

Dr. Johnson visited with us, examined Henry, and took a detailed family history from both sides of our family. Then with a few quick blood tests made a presumptive diagnosis of spontaneous (meaning no family history) Classical Hemophilia or Von Willibrands Disease (another type of Hemophilia that has an accompanying platelet defect). She explained that without more comprehensive tests, she could not distinguish between the two. She also described an immediate treatment that should stop the bleeding.

Dr. Johnson called Dr. Roberts and discussed giving Henry a transfusion of a pooled blood concentrate, called cryoprecipitate, which was rich in Factor VIII, the protein that most Hemophiliacs are lacking. Dr. Johnson explained to Dr. Roberts that she would prefer to use a more expensive and newer blood product called Factorate™, which had less foreign protein and only contained the specific protein missing in Classical Hemophilia. If an infusion of Factor VIII stopped the bleeding, that would prove that Henry had Classical Hemophilia. An infusion of cryoprecipitate would also stop the bleeding but would not answer the questions of Hemophilia or von Willibrands. Dr. Roberts, trying to save the Army and the Federal government money, wanted the cheaper treatment. While the doctors discussed the merits of the hypothetical treatment, Henry, who was playing on the rocking horse, rocked on a bit too much and fell onto the wooden head of the horse, cutting his lip. He was now bleeding from his chin and from his lip.

Dr. Johnson overruled the interest of the Federal Government and decided to infuse Henry with the more expensive Factorate ™. Within minutes, both the cut on Henry's chin, which had been bleeding for more than a week, and the cut on his lip (only twenty minutes or so old) had stopped bleeding.

Henry had Classical Hemophilia, a Factor VIII deficiency. Joan and I knew that our world was changing, drastically! We left the doctor's office in a state of shock. We had both heard of Hemophilia and we both remembered the genetic transmission from parents to child. We were both able to draw the Punnett square, which is used by biologists to determine the probability of an off spring having a particular genotype.

[1] In the End Notes there is a detailed description of the Punnett Square and the determination of gender based on the contribution of X and Y chromosomes by the parents.

What we did not know was that the ability of the blood to clot depends on a series of complex interactions of protein combinations. These proteins must interact in a specific chain reaction, almost like dominos lined in a row. If one of the dominos is missing, all of the ones past the missing domino remain standing and the blood does not clot.

[2] In the End Notes there is also a detailed description of the genetic transmission of Hemophilia.

We could easily understand the genetic toss of the dice that helped to determine our children's gender and Henrys' Hemophilia. What we did not understand was the effect Hemophilia would have on our family. We could not have begun to imagine how much our lives would change.

We were about to get a lesson.

Hemophilia

The months after Henry's diagnosis with Hemophilia were a blur. Joan and I, both already voracious readers, immediately devoured everything we could find about the disease. In addition to everything we could get our hands on from the doctor's office, we both reread the book *Nicholas and Alexandra*. We learned that Robert Massie, the author, had a personal reason for studying the doomed last Czar of Russia whose family was afflicted with Hemophilia. This rare disease also affected Masse and his family.

As Massie investigated the story of the Russian Tsarevitch Alexis, he learned that Alexis had inherited Hemophilia from his mother. Alexis's mother inherited it from her mother, Alice, who inherited it from her mother, Queen Victoria of England. Queen Victoria was a "carrier" of Hemophilia and arranged the marriages of her children to European royalty in Russia, Prussia and Spain spreading the disease to the royal families on the European continent. This is the reason why Hemophilia is sometimes called the "Royal Disease."

We also discovered that Robert Massie had written a second book, *Journey*. The book, co-authored with his wife Suzanne, told the compelling story of their family experiences in raising their son, Bobbie, who had Hemophilia. Their story detailed what it was like living with Hemophilia.

Journey became a bible for us. The Massies' revelations of their many trials and tribulations helped to normalize our lives. Although prevalence rates vary, it is assumed that about 1 in 10,000 people have Hemophilia. Meeting someone with Hemophilia was a rare occurrence, and finding the book by the Massies was a Godsend.

Their book confirmed what we were experiencing. Guided by our physicians (we now had several) and the lessons revealed from *Journey,* we set out to live as normal a life as possible.

Dr. Johnson had explained to us that Hemophiliacs rarely died of their disease. The popular misconception of uncontrolled bleeding was not the reality. Hemophiliacs tend to bleed into underlying tissues, forming big, sometimes ugly and swollen bruises. Henry frequently looked like a battered child. Prior to his diagnosis, we had assumed that his frequent bruises were the result of his being an active child. Now we learned that those bruises were exacerbated by his bleeding condition. Bruises, although unpleasant, often uncomfortable and sometimes painful, were not often serious. The blood lost into the tissues would be reabsorbed by the body.

2. Henry on bike w/ black eyes.

We learned that the most likely danger to Hemophiliacs was bleeding into joints. Because joints are rich in blood vessels and grow quickly in children and are subjected to stress from walking, running, jumping, and movement, they are the sites of frequent bleeding episodes. Hemophiliacs frequently bleed into their joints, often with no known trauma. Knees are most susceptible. The blood in a joint collects in the synovial or joint capsule surrounding the bone and acts like a caustic agent on the bones. Repeated bleeding into any joint, but most often the knees, ankles and elbows, would result in a severe arthritic-like condition, making moving and walking very painful or even impossible.

Head injuries were the rare exception. Head injuries of almost any kind could be life threatening to Hemophiliacs because uncontrolled bleeding in the brain could lead to death.

For generations, Hemophiliacs, like Henry, were forced to endure the pain of joint bleeding because there was no

treatment. When blood transfusions became possible in the 20th century, it was still a poor treatment for Hemophiliacs. The amount of the missing protein in a unit of blood was not enough to treat a Hemophiliac without the transfusion of large quantities of blood. That was impractical, expensive and dangerous to the patient.

Then, an improvement in treatment came with the discovery of cryoprecipitate. Cryoprecipitate means "cold precipitate." Fresh frozen plasma is slowly thawed and, just before melting, a white precipitate forms, which is separated by a centrifuge. That precipitate is rich in the protein missing in people with Hemophilia or Von Willibrands disease. Instead of receiving massive quantities of blood, a patient now could receive the missing protein using a tiny fraction of the amount of fluid volume. By taking the "Cryo" from several bags of blood and pooling it together, it became possible to give a patient enough of the missing protein to make clotting normal. The effects of the treatment lasted for about twenty-four hours, but it was enough to get the clot necessary to stop bleeding at an injury site. In some injuries, more than one treatment was necessary. As we were to discover in time it was not unusual for Henry to be infused for several days or even weeks until the bleeding had stopped.

Another alternative to using cryoprecipitate was discovered in 1968. A group of researchers working for a drug company named Hyland Labs found that they could pool the Factor VIII from hundreds or even thousands of donors and further refine it. They then could freeze dry it, pack it in little bottles, and with one small injection or "infusion" a Hemophiliac could be given normal clotting ability. That is Factorate ™ the expensive product that Dr. Johnson used to diagnose Henry. Henry should not have to suffer the effects of prolonged bleeding into his joints.

Dr. Johnson explained that in time we could learn to infuse him with both "Cryo" and Factorate ™ at home. She assured us that, if we treated our son quickly and aggressively at the first sign of bleeding, there was no reason why Henry could not live

a normal, healthy, long life. We loved her news, her compassion, and her manner of assuaging our fears. She made us feel as though everything would be all right. She did not know it, but she was wrong, dead wrong.

Our family settled into the new status quo, and I returned to my assignment as a military police officer / investigator working with the 140th MP Company a garrison unit at Fort Gordon, Georgia. We moved across post to nicer housing so we could be nearer to the school where Jennifer would attend first grade.

Then I began to notice subtle changes in Joan. She seemed to depend more and more on her family than before. She spent considerable time on the phone talking with her mother and her sisters, they were trying to understand the source of the afflicted **X'** chromosome that caused Henry's Hemophilia. Rosemary, Joan's mother, told us that Joan's maternal grandfather had given up a promising career as a boxer at a young age because of uncontrollable nose bleeds. Once, after a tooth extraction he nearly bled to death. At the time, it did not seem that unusual.

At the suggestion of Dr. Johnson, Joan and I took our family to Atlanta to the Center for Disease Control for further testing. This testing included a new, state of the art platelet aggregation test that measured how well the platelets stuck together in the clotting process. That test confirmed what Dr. Johnson had diagnosed. Henry had classical Hemophilia or Hemophilia A. The additional testing also indicated that Henry also had Von Willibrands disease. The testing showed that he did not have normal platelet aggregation or clumping. The statistical probability of one person having two bleeding disorders seemed almost impossible. It was very unusual, but Henry had both Hemophilia and Von Willibrands disease. Although it was a statistical anomaly, and his treatments would be more complicated, we were told by our treating physicians, "We don't treat disease. We treat patients." The treatment in those early days was almost the same for both classical Hemophilia and Von Willibrands disease.

In the future we did additional genetic testing in Joan's family. That testing showed that my mother-in-law and each of Joan's three sisters were carriers. However, none of her three brothers had gotten the X' chromosome that causes Hemophilia. Because girls are mostly asymptomatic, no one knew. Joan's grandfather died without ever knowing that he was a Hemophiliac.

The unlikely presence of two different types of Hemophilia was curious but made no difference to us or to the treatment. "Cryo" became the preferred treatment, but Factorate ™ was faster and easier to use. When things were more critical, we tried to use Factorate ™ and then sometimes we would switch to "Cryo" for the continuing treatment. Except for being a statistical oddity Henry's two-disease diagnosis didn't really matter.

As time went on, the tension of having a chronically ill child with a life threatening disease increased. We learned that Henry would not need to be treated for every injury, but whenever he fell or twisted an ankle or knee or bumped himself, we did need to be hyper vigilant. Henry in time learned when he needed treatment for injuries. He could feel the bleeding inside his joints and tissue. As he got older, in time Henry learned that he was the best predictor of the need for treatment for his Hemophilia.

However, the thought of head injuries were terrifying to us as his parents. Even the slightest head injury could be life threatening. Some sports like baseball and any activities with substantial risk of head injury would be out of the question for Henry. The risk was not worth the benefit.

The state of hyper vigilance, of being constantly on guard was stressful for both Joan and me. Joan needed more support from her family. Phone calls home to her mother were increasingly frequent and long. Joan was upset much of the time; and occasionally, even depressed. One night after coming home from a late evening shift as the duty investigator,

I found Joan waiting up for me. The kids were sleeping and everything seemed fine, but Joan had been crying.

I asked her what was wrong. "Nothing," was reply. We had been married for more than six years. I knew she was not telling the truth. Later that evening, several hours into what became a long and sleepless night, Joan revealed her concerns for our children. Each of them had inherited the Hemophilia **X'** chromosome from Joan and she blamed herself.

Joan explained that it was all her fault that our children had Hemophilia. Each of our grandchildren would also have a 50% chance of getting the same **X'** chromosome that caused Hemophilia, she explained. They, too, would then have Hemophilia. It was all her fault. Of course I thought that this thought process was ridiculous!

I tried logic. I tried explaining how it was also Joan's "fault" that the girls had beautiful red hair and freckles. But my approach was totally ineffective. Finally, I remembered the book—*Journey*, where Suzanne talks about the guilt experienced by mothers of Hemophiliacs in having "given" their children Hemophilia. Because the chromosome is carried by the female, I suppose you could use some twisted logic to try to explain fault. I reminded Joan that this was the same emotional response experienced by Suzanne Massie. There is comfort in knowing that you are not alone, knowing that others have experienced the same things. We talked long into the night and finished our discussion just as Jennifer woke up to get ready for school. Nothing was resolved, but talking about it and sharing concerns seemed to make our problems more easily managed.

3. Henry, Diana, Jena @ Fort Gordon

Life was good in spite of our newest challenges. We were learning to deal with issues of having a child with Hemophilia.

Henry wasn't having any special problems and, except for his red medic alert tag, he looked and acted like every other active child his age.

We liked living in Augusta, Georgia. The Atlantic Ocean was only a few hours' drive from our home. We loved exploring the beautiful beaches of South Carolina and the area around our favorite beach, Edisto Island. Joan would collect sea shells for hours. The kids and I loved to play in the warm surf. One bright sunny summer's day, Joan and I were swimming in chest deep water just beyond the surf and the gently breaking waves. Our three children were all playing in the scattered sea shell filled warm white sand nearby when Jennifer (always precocious) stood up, pointed directly at Joan and me in the water and shouted. "Daddy, Daddy, a whale!"

Joan and I turned around and saw the shadowed shape of a huge fish swimming in the water just below the surface directly towards us. Its dorsal fin exposed, high out of the water, the fish was ominously slicing its way toward us just yards away. Like the rest of the movie going world, we had recently seen the movie *Jaws,* and **"SHARK"** that was all either of us could think of. We held hands and made for the beach as fast as we could when a huge, gray and black colored beautiful dolphin leapt out of the water. We were nearly scared to death, but at the same time instantly thankful that we had not met the shark from *Jaws.* Jennifer was almost right. It wasn't a whale, but it sure wasn't a shark either.

Often we would camp on the beach, cook and eat hot dogs and coleslaw for dinner and explore the nearby tidelands. Closer to our home and near the army base was a great recreational area named Clark Hill, which was built as a flood control project that created a large man made lake. We enjoyed fishing, camping, hiking, boating, swimming and being together. Soldiers don't get paid very much and, although we did not have much money, we were fortunate. We did have time together, and we had each other. As young as we were, we already valued our time together more than anything else.

Our lives continued normally for most of 1975, and our house became the "Kool-Aid house" of our neighborhood. It was the one house in the neighborhood where all the kids seem to collect and to play. Because we had a large yard and three children aged two, four years, and six years old, it was not uncommon to see children of all ages playing in our front, side and back yards. The role of super-mom suited Joan well. She settled into being a full time mother and caregiver to our children while I settled into my job as a military police officer. In September, I was sent on temporary duty to Fort McClellan, Alabama, about 250 miles or five driving hours from Fort Gordon.

My temporary duty assignment only required that I be at Fort McClellan Monday through Friday for school. I commuted on Monday to McClellan and back to Gordon on Friday. This routine continued for eight weeks. In the last week of training, the final exam was scheduled for Thursday, November 6th, and a graduation was scheduled for Friday. Since I had a 100% average test score and was going to be the Honor Graduate of the class, I was excused from taking the final exam. On Wednesday, November 5th I drove home 250 miles in 5 hours to spend an extra day with my family. I would have to return to Alabama on Thursday afternoon for the Friday graduation.

Joan was pleased at the surprise and it almost made up for having missed our wedding anniversary three days earlier. We celebrated Wednesday evening. Thursday morning, I slept in. Joan had to get Jennifer up to go to school. Jennifer was tired. The excitement of dad coming home mid week had caused a later than usual bed time. Joan and I hung out together and after lunch I began to pack for my five hour drive to my graduation from investigator's school. Jennifer came home from school at about 3 PM. As usual our front yard quickly turned into a playground of children ages 2-8 from all over the neighborhood. The weather was warm, even for Georgia in November. The kids were wearing shorts and some were barefoot. Joan and I were sitting on the couch talking, the kids were playing. Henry wanted Jennifer to push him on his tricycle. Jennifer, at six already an expert at delegating, sent

Henry to get the tricycle. Then over the din of children's voices, in a clear but excited voice, Jennifer cried out,

"Mommy, Daddy, Henry has been run over by a car!"

Joan and I flew through the door and both arrived at the driveway in the same instant. A neighbor had backed her car into our drive way and was turning around. As she turned the steering wheel, the front end of her huge yellow four-door Dodge Monaco swung widely in our driveway and ran over Henry sitting on the tricycle. There were at least six children in our yard. What are the odds that the child who has Hemophilia (1 - 10,000 people) and who has a second bleeding disorder (Von Willibrands disease) would also get hit by a car. The odds didn't matter, Henry defied them again. Henry had been the one who had been hit by her car.

When Joan and I got to Henry, he was still under the car. The tricycle had been crushed. Henry lay tangled in the mangled frame. Thankfully, the woman stopped when Jennifer called out. If she had continued in either direction, it would have been worse. The children were all crying, Henry was screaming. Joan was trying to comfort him. I quickly assessed the situation and saw that his right ankle was still under the tire. He was bleeding from some small cuts on his face and lip and had broken a tooth. Thankfully, he was alert and conscious. As Joan held our son, I very slowly and carefully directed the driver to pull the car forward just a few inches. As the car rolled forward, Joan slid Henry's crushed foot from under the right front tire and rescued his tangled and broken body from the twisted frame of the tricycle.

4. Henry's tricycle

As soon as Henry was clear of the entanglement, I rushed inside the house and called my co-workers at the Military Police Desk. They all knew about Henry and his Hemophilia. We lived eight miles from the Medical Center. I asked the desk sergeant to notify the Emergency Department of the hospital that we were bringing in a Hemophiliac with life threatening injuries. I grabbed a towel from the clean wash basket in the living room and rushed back outside to our car where Joan was already sitting in the front seat, holding our crying son. Joan wrapped the towel around Henry's foot and tried to comfort him.

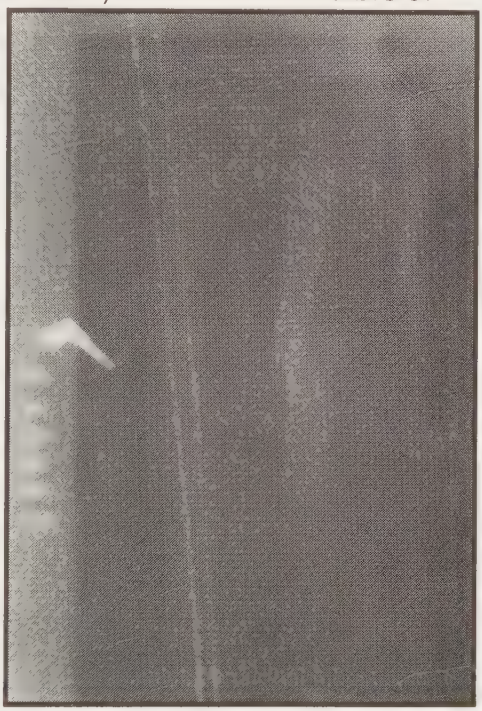
A neighbor woman from across the street who had gathered with the growing crowd of interested spectators offered to take care of Jennifer and Diana until we returned.

Careful not to hit any of the many gathered people in our driveway and on the street, Joan and I began the longest eight mile drive of our lives. Henry was crying. Joan was amazingly calm and comforting. I was focused on the driving. As a police officer, I had taken a course in Emergency Vehicle Operations. Ours was a small blue Toyota Station Wagon. I put on the flashers and sped where it was safe to do so. When we came to the red lights, I drove around them, breaking every traffic rule in the book. I went through the intersections slowly but aggressively. I am sure many people were offended. I was careful but assertive.

When we reached Fort Gordon, I could see that the post gate guard had stopped traffic to let us through. He then radioed ahead to stop traffic at the next two intersections before the hospital. We got there in less than 10 minutes. As we arrived, doctors and nurses came out to meet us with a gurney. Joan reluctantly surrendered our son to their care. Joan went inside the Emergency Department with Henry while I parked the car. When I returned from parking the car, I was surprised to discover that the woman who was driving the car that hit Henry was also already at the hospital. It took me several moments to realize that she had ridden with us in the back seat of our car. She, too, was worried and concerned and wanted to do what she could to help. Realizing that there was nothing she could do at the hospital she called her husband

(who like me was a soldier) to come and get her. We were both touched by her concern and desire to help. Joan and I stayed with Henry for the routine exams of a thoroughly trained and expert group of Army physicians who were not used to examining a child, especially a child with Hemophilia.

The most serious injury that Henry had was not visible or even known to Joan or to me. When his tricycle was crushed the collapsing tubular frame broke his left femur. The femur is the long bone that connects the hip to the knee and is surrounded by the thigh. In Henry's case, the femur was not just broken but it was shattered, twisted and broken in multiple pieces. In medical terms it is called a spiral oblique comminuted fracture. Breaks don't get much worse. A break like that also meant that Henry would loose about 20% of his blood supply into the muscle surrounding the bone. There was not enough "Cryo" at Fort Gordon to treat him for more than a day. The Army transferred more blood from Fort Knox, Kentucky by helicopter that night.



5. X-ray showing broken femur

Henry was admitted to the hospital in intensive care. Joan and I went home to get Jennifer and Diana from the neighbors. We knew that they were worried and scared, just like us. We tried to calm them. Jennifer blamed herself for Henry's accident. She said "if I didn't tell him to go to get the tricycle, he would not have been hit by the car." We reassured her that,

in reality, she had saved his life. If she had not called to us and the car kept backing up, Henry would have been dead.

Joan, Jennifer, Diana and I all slept or tried to sleep that night, Henry was spending his first night in a hospital away from his family.

Henry spent the next two weeks in a traction device that used the muscles of the thigh to force the bone of the femur into the right place. The chips of the bone, clearly visible in the X-ray, were held in the correct place by his thigh. His little body was slightly suspended from the surface of the bed. The weight of his body kept the broken bone and his leg straight.

6. Henry in ICU w/ "Femur"

In summary, his left leg was fractured. His tooth was broken. He had cuts and scrapes on his face and lip. His right ankle had been crushed but, amazingly, nothing there was broken. The woman driving the car came to visit him once in ICU and gave him a stuffed dog that was bigger than Henry. Henry named the dog "Femur." What else could it have been! He had recently heard the word a lot.

The two weeks of Henry's hospital confinement flew by. At my request, my sergeant assigned me night duty so I could spend the day time with Jennifer and Diana while Joan stayed at the hospital. Nights, Joan took care of Jennifer and Diana and I patrolled the halls of Dwight David Eisenhower Medical Center. There was no crime there on my watch!

One of the nice things about the "Big Green Machine" that we lovingly called the U.S. Army is that we take care of our own. There was not a request I could make where there was not a special effort made to fulfill it. It was very much like a big family.

They all knew Henry.

Just before Christmas, Henry was sent home in a SPICA or full body cast. The cast went from above his nipples on his chest to his toes on his left foot and to the knee on his right leg. The cast weighed more than he did. Poor Henry, who was just learning to be potty trained, found himself back in diapers and helpless to do anything about it. He couldn't even roll over when he came home.

The timing of his release from the hospital was perfect. We were able to go home for the holidays to show off our son and our daughters to their worried grandparents on both sides of our family. Hank and Irma, Tom and Rosemary were worried about the grandchildren and about Joan and me as well!

Henry looked like a

7. Henry in SPICA cast

huge, misshapen, uncoordinated turtle when we loaded him and our two sleeping daughters on the back deck of our Toyota station wagon as we began our journey to New York for the holidays.

Joan and I had learned to drive from Augusta to New York at night. We would depart for our trip home just as the kids were getting ready to go to sleep at about seven or eight in the evening. The drive was just under 900 miles or about eighteen hours with breaks from Fort Gordon to Joan's parents' house north of New York City. The kids would sleep through the night with Joan and me alternating driving duty with napping. When the kids woke up at seven in the morning, we would stop for breakfast and get cleaned up. The last seven hours of the trip was spent finding ways to entertain the children for the final leg of the journey. We would arrive at the grandparents' home early to mid afternoon, in time for the kids to play a little before bed. Then all of us would wind down for a good night's sleep.

Christmas, 1975 was spent celebrating our success over the tribulations of the last year. We had been through a lot. Henry had been diagnosed with a rare, chronic, and potentially life threatening condition. He had been hit by a car and had serious injuries. We were learning to live with Hemophilia and we had convinced ourselves that it would not be that big a deal. Little did we realize that our education and our experiences had only begun. After celebrating the holidays for nearly ten days with our families, Joan and I began the long drive from New York to Augusta with our three sleeping children in the back of our blue Toyota station wagon.

When I returned on Saturday, January 3rd, 1976 to my Military Police Company area, I checked my mailbox. Waiting in the college dorm style mail cubicle was an official-looking US Army envelope, thick with papers. Well, this wasn't expected! With trembling fingers, I tore open the envelope and, with concerned anticipation, I read the contents.

Orders: Specialist Henry J. Nicols is hereby ordered to report on January 6, 1976 to US: Army transfer station for

immediate reassignment to Military Police Investigations Duty Station to be determined on arrival in Frankfurt, Germany.

Well, this certainly wasn't good.

Joan and I had hoped to go to Germany. I speak German. I have family in Germany, and this was part of the plan. Only the plan wasn't to do it NOW! Henry was still in a cast. Leaving now would give Joan the complete responsibility to deal with all the troubles and issues relating to Henry's lengthy recovery and to the care of two other small children. While Joan was fully capable, I wasn't at all sure that I was able to leave my wife and children alone in Augusta, Georgia to confront the issues they would be facing in the next few months.

I scheduled a meeting with my Commanding Officer. He was a Captain who liked me and had tried to talk me into going to Officer Candidate School. I wasn't interested. My brief experience in the Army had confirmed my belief that officers administered. Enlisted soldiers did the work. The reason I enlisted was that I wanted the experience of being a cop, not the experience of being an administrator. I was too young to administer anything! I wanted to have fun and police work was fun. The Captain liked me in spite of my obstinate attitude and my refusal to go to O.C.S. He knew that I was a good cop and investigator. He was familiar with our family situation. He invited me into his office.

"Close the door." He said, as I entered his dull, olive drab, uninteresting office. It was unusual to close an office door unless there was something he wanted no one else to hear. Our conversation went something like this. I spoke first.

"Sir, I have orders to report for transfer to Germany on January 6. That is three days from now."

"I know that." He said unemotionally.

"Sir, I want to go to Germany. It is my station of choice. I just don't want to go now. Henry is still in a cast. He is getting blood transfusions daily as they get ready to take the cast off. He has to go through physical therapy. This is a bad time!"

"I know that, too." He displayed no look of sympathy.

"Sir, I can't go now." I must have looked desperate.

"I know that. Listen, Nicols," he had obviously considered my situation and had a recommendation prepared. "You are on the MPI (Military Police Investigations) schedule next week, too. I suggest that you continue working in MPI and let's see what happens."

It was obvious to me what my commanding officer was doing. He couldn't rescind my orders. They came from very high in the Army food chain. The Department of the Army never did anything quickly. There wasn't even time for an emergency delay of orders.

On Tuesday January 6, the day I was supposed to be on my way to Germany I reported to the company area and saw Specialist Bird, our company clerk, to ask why my mail box key no longer worked.

"Nicols, your mail box has been closed. I reassigned it to a new guy this morning. You are not supposed to be here. You have orders for Germany. You are supposed to be on your way today!" He was clearly annoyed and obviously did not know about my discussion with the Commanding Officer. "You are AWOL!" (Absent With Out leave).

"Hey, Bird, I can't be AWOL. I am still on the duty rooster." I said. "And I am standing right here!"

Specialist Bird checked the wall behind him. I was indeed listed as the duty investigator for the day. Then he looked to make sure I was indeed standing in front of him. Then he scratched his head and said,

"I don't know what to do!"

It became obvious to me over the next few days that it wasn't just the company clerk, Specialist Bird, who didn't know what to do with me. It was the Army. I was given a delay of orders until Tuesday, March 30th.

During the weeks that followed, in rapid succession and after completing the requisite multiple copies of the piles of army paper work I asked for:

1. A compassionate delay of orders until Henry was finished with his treatment and physical therapy. Denied!

2. Compassionate reassignment to Fort Gordon, Georgia. Denied!

3. Compassionate Reassignment to Frankfurt where there was a large hospital that could treat Henry. Denied!

Then I asked for another meeting with my Commanding Officer. He explained to me that since all my requests were because Henry had a chronic condition that would never get better, Hemophilia; if I were granted a compassionate reassignment, I would have a permanent reason for reassignment, and the Army didn't want soldiers with travel or assignment restrictions.

I immediately understood. I was not eligible for compassionate reassignment. I was, however, eligible for compassionate discharge. If the army couldn't dictate when and where I would go, it would rather that I left.

Joan and I discussed it. The Army didn't know what to do with us, and we didn't know what to do with the Army. On Tuesday, February 10th, I submitted paperwork for a compassionate discharge from the US Army.

It should have taken the Army just over two weeks to process my papers. But the Army, doing what it does so well, lost my paperwork.

On Monday, March 1, 1976, I submitted duplicate copies of my request for compassionate discharge. (I knew that they might lose the paperwork). I hand carried the second copy from person to person to get the requisite signatures.

On Monday, March 9, 1976, I was notified that I was discharged effective March 10, 1976. It wasn't just me that the Army didn't want. The Army didn't want the issues of dealing with a family with a child with a life-long, chronic and serious life threatening medical condition.

On March 10, 1976, I left the Army and was once again a civilian. The next day Joan and I packed our car and our rented U-Haul trailer and began the long drive home to New York.

We had no job, no place to live, and no plan. But we were together! We moved in with my parents, who lived in Catskill, New York, and I began to look for a job.

Hancock to Cooperstown

Using a road map, Joan and I drew a fifty mile circle around Oneonta, the place we had first met and started our family. We thought that, if we could find a hospital to treat Henry and a job for me, we could start over there.

After leaving the Army, both Joan and I felt like our world had been turned upside down. Not only were we dealing with the issues of Hemophilia but related insurance issues as well. We had tried to get family health insurance so we would be covered between jobs. The insurance company accepted everyone except Henry. We discovered that Henry as an individual was uninsurable. It was necessary for us to always maintain a family health insurance policy through a large group insurance program. Working as a civil service police officer would offer that kind of insurance.

In short order, I was offered a job as a police officer in Hancock, New York with the hope and potential of becoming the police chief of that small department within a year. We liked Hancock. It was in the same Catskill Mountains, where our beloved summer camp was and it was at the headwaters of the Delaware River. The Mayor and the Village Board wanted us. There was a hospital about 45 minutes away in Binghamton with a physician who had experience treating Hemophiliacs. We started to settle in to our new lives. Hancock was good for us.

We all settled in to our new lives. Jennifer attended the Hancock elementary school, and Joan took a job as a police dispatcher for the Hancock Police Department. We had a police phone and radio in our home. In between dispatching the one or two on-duty police officers, Joan could care for and play with Diana and Henry in our home.

Henry's Hemophilia seemed very manageable in those days. Although he would need an occasional transfusion most of the

time there was no way to tell that there was anything unusual about Henry or our family. Not only did we not feel abnormal, we felt quintessentially normal. It was an easy and a good way to live.

I was an advisor of the local coed Scout Explorer Post, and in that role was able to return to outdoor adventures. We canoed, hiked, and backpacked. We spent lots of time together as a family and we all continued to grow in dealing with Henry's Hemophilia, and the constant vigilance required in managing the issues of chronic illness.

About six months after our family's arrival in Hancock, I was appointed "Acting Police Chief." "Acting Police Chief" meant that I had all the responsibilities and headaches of being the police chief and none of the civil service protections. It was responsibility without privilege. It was about that time that New York State offered a civil service police chief's test for central, upstate New York. Although Hancock had no intention of appointing a civil service police chief (the Mayor and Board liked the flexibility and lack of commitment of having an "Acting Chief,"), I took the test just to qualify. My experience as a school teacher prepared me well for test taking. The civil service test was rather easy. I received the official notice that I had scored number one in the region. It was with great pride that I reported my score to the mayor and the Board of Trustees, who although suitably impressed still had no intention of naming me or anyone as the formal, official, civil service police chief.

An unexpected outcome of my success on the civil service exam was the invitations that I received from other communities to interview for their open positions as police chief. To my surprise and joy, Cooperstown, (the birthplace of baseball and home of the National Baseball Hall of Fame) called and asked me to interview.

Cooperstown, located only twenty miles from Oneonta, was the epicenter of our desired living area. Joan and I were familiar with the beautiful summer resort community.

In late August of 1978 Joan and I drove to Cooperstown for my interview and to explore the community. To our delight, we discovered that there was a major medical center there called Bassett Healthcare. Not only were their physicians familiar with Hemophiliacs, but on staff were pediatric hematologists who had considerable knowledge about Hemophilia. It seemed like a match made in heaven. The Village Board and the Cooperstown police department interviewed me, and Joan and I interviewed the physicians and Bassett Healthcare. Largely because of the hospital, Joan and I decided that, if offered the job, we would move to Cooperstown. That evening Douglas Walrath the Cooperstown Village Clerk called me and asked how soon I could start. Although we had not planned it, after just two years in Hancock, we sold our house and moved to a smaller one in need of repair on the shores of Goodyear Lake near our new community of Cooperstown.

We did not know it yet, but Cooperstown was a perfect place for us to raise our family. Jennifer was young enough to enjoy new adventures with her family without the regret of leaving her classmates. She was happy to move to a lakeside community. All three of our children made new friends easily, and they quickly adapted to their new surroundings. Because we lived on a lake, we had a boat tied up in the back yard and spent many evenings fishing, swimming and snorkeling right from our own backyard picnic table. As a family we had always stayed active in outdoor sports and, as I had done in Middleburgh and again in Hancock, I remained active in Scouts this time as the Scoutmaster of the local Boy Scout Troop 1254 in Cooperstown.

Bassett Healthcare was a great resource. Multiple physicians trained as hematologists were not only capable of caring for our son but seemed genuinely interested in his care. They knew more than Joan and I had learned in our experience in dealing with Henry's injuries and illnesses. Dr. Pedro de Alarcon was Henry's pediatric hematologist. He quickly developed a relationship with our rough and tumble son who

never let his chronic and life threatening condition slow him down.

Joan and I went with Henry the day he started kindergarten. We met with his homeroom teacher and the school nurse, the gym and other specialty teachers. In time we taught the teachers what we knew about Henry and his condition. We wanted them to know that he was basically a normal child who happened to have Hemophilia. We asked them to treat Henry normally, and we requested that they not be hyper vigilant or super cautious with him any more than they would be with the other students. If Henry should get hurt, he could be treated. As far as Joan and I were concerned, the most important thing that we could ask of the school faculty and staff was to teach our son that he was not special or disabled.

As a child Henry was fairly obedient but he had a way of doing things that tested the limits of parental understanding and tolerance. His bicycle stunt was one of those times. More than one generation of boys including Henry grew up with the idea of becoming the next Evel Knievel. Knievel was of course the motor cycle dare devil who specialized in outrageous motor cycle jumps, including one of his last that nearly killed him when he attempted to jump across the Snake River Canyon. Knievel began his motor cycle dare devil antics on a bicycle. When he retired from the sport there was a vacancy in the world for a professional dare devil. Henry and his friends desired the job, so they built a bicycle jump out of some scrap plywood and cement blocks. They had "borrowed" the blocks from the construction project that was replacing the roof of our fixer-upper house. They used the materials to make an adjustable angled ramp where the plywood could be raised and lowered to change the distance of the flight pattern of a speeding bicycle. The boys even had a grassy area designed for the planned landings. They worked hard at their project and spent a whole morning designing and building their launching pad. The decision was made to do the first trial jumps immediately after they returned from lunch at their separate homes.

While at lunch, Henry spilled the beans to his mother. He never was very good at secrets and even worse when it came to keeping secrets from his mother.

"There is no way you are jumping off of a ramp with your bicycle." Joan commanded.

"Yes mom." Henry said dejected and sorry he had not kept the secret of the bicycle jump.

"And I don't think the other boys should be using their bicycles to jump off a ramp either." Joan continued.

"OK mom. I will tell them." Henry said surrendering.

True to his word, Henry went back to the ramp site and, as he had promised, told the boys that he would not be able to jump his bike off the ramp. He also relayed that his mother didn't think that the other boys should be jumping off of the ramp either.

Henry and the boys carefully discussed Joan's ultimatum. After significant discussion, they decided that Henry's mother only thought that they should not be jumping their bikes. She had not forbid them. A strict interpretation of the statement meant that Henry was the only one who could not jump his bike. The others were not technically in violation if they did jump their bikes. Henry's mother ultimatum was not necessarily binding on all the boys.

So it was agreed that they (except for Henry) could jump their bikes over the ramp. It was further agreed that Henry would lie under the ramp to provide an element of danger for both the airborne cyclists and for the person lying on the ground. Henry's mother had forbid his riding his bike over the ramp but had not excluded him from lying under the ramp when the others jumped over him on speeding bicycles. This dare devil antic ended when the ramp collapsed and a flying bicycle crashed into him. The boys ran to get Joan who needed

to transfuse Henry on the front lawn with his dare devil brothers all watching.

He was an obedient child according to the letter of the law, just not the spirit of the law! His pattern of risk taking was starting to develop and considering my own risk taking history, I thought that the apple had not fallen far from the tree. Henry was a product of both the nature of his illness and the nurture of his family in general and his father in particular.

Henry could risk the normal injuries of childhood but head injuries continued to be scary. Henry had lots of injuries that required treatment. One day, he was climbing a chain link fence to see what was on the other side. As he scaled the fence, he fell, gouging a patch of skin from under his arm pit. He needed to be transfused.

8. Henry w/ bump

Another time, he stepped on a pitch fork left in the yard. He needed to get tetanus shots and be transfused for days after as well.

As predicted the most common injuries were knee and ankle bleeds. Because of his car accident, Henry had a higher risk for bleeding in both his right ankle and left knee. The broken femur caused his left leg to be longer than the right. Until he was bigger and his hips were further apart, he needed to wear expensive lifts in his shoe. The lifts would help avoid his having to tilt his back at an awkward angle and potentially develop bleeding in his spine. Often infused for knee and ankle injuries, Henry was frequently hobbling around on crutches. During especially bad times, Henry would be restricted to a wheel chair. His knees or ankles or both became too weak or injured to support even his own weight.

During one family vacation, Henry was in a wheel chair. We were exploring Washington, D.C. and the environs including Busch Gardens in Williamsburg, Virginia. We owned a huge white van nicknamed "Moby". That van carried our entire family, Henry's wheel chair, and medical supplies. When we got to the Busch Gardens amusement park, we were pleasantly surprised to discover that Henry's wheel chair got the entire family to the front of the long lines that gathered at the most popular attractions and rides. This worked out well for all of us. Jena and Diana were old enough, however, to resent the special treatment of their brother, even if it meant special consideration for all of us. They disliked the extra attention that he was getting. Even more annoying was that Henry enjoyed every minute. After going on several roller coaster and water slide rides, we all took a break for lunch in one of the Busch Garden picnic areas. As Joan and I were cleaning up from our picnic, Henry asked for ice cream. Diana, at age nine, was her mother's little helper and was already busy assisting Joan. So I asked eleven-year-old Jennifer to push her seven-year-old brother to the ice cream stand to get ice cream for all of us. Jena already annoyed by the special treatment resented pushing Henry, but she too wanted ice cream.

Reluctantly, she agreed. Armed with a ten dollar bill, Jennifer pushed Henry in his wheel chair as they headed off to buy the five ice creams. As they crossed the patio, fifty yards from where we were, one of the small front wheels of the wheel chair got caught on a crack in the patio stones. The wheel chair tipped over. Henry, the wheel chair and Jena all spilled out across the patio in front of the ice cream stand in the middle of the lunch time picnic crowd.

Joan and I had not even noticed, but a crowd immediately gathered around our two children. Jennifer quickly got up. Henry was still lying on the ground crying, the wheel chair was still on its side with a wheel spinning. Joan and I were attracted by noise and decided to investigate. There was Jena standing

over her obviously injured distressed and crying little brother yelling in her loudest eleven-year-old voice,

"Get up, you little cripple! Get up!"

Joan and I rushed over to rescue both Jena and Henry from their predicament. I am sure many of the people there just did not understand how Jena could be so heartless. Once we were sure that the kids were O.K., we all calmed down and later even laughed about it.

I guess you would have to live with Henry and Jennifer to appreciate the humor of the event. To this day, we remind our older daughter of her moment of indiscretion, which still causes her more than a little embarrassment! Oh yes, and I went back to get the ice cream.

Henry, Diana, and Jena were in many ways much better prepared for life's unusual, unexpected events than normal kids could be. Normal to us was unusual. We came to expect the unexpected, and we appreciated the typical things so often missed by many people.

Pedro (Henry's doctor) had told us that families who experience a chronic illness often grow more closely together because of the bonds forged in the stress of the illness. Pedro said that we would learn lessons other families couldn't begin to understand. I think he was right. Our family vacationed and travelled as often as we could-- camping, hiking, and picnicking to save money-- but we were spending time together.

Because my income as a police chief of a small town was barely enough to support our life style of family fun and adventures, Joan and I agreed that extra income would be helpful. Joan accepted a position at Bassett Healthcare working as a nurse's aid. Although the pay was not much, we thought it fair as Joan had never finished her degree. She was too busy raising our children and supporting me. Although this combined income was not a fortune, we were reasonably well off. We paid most of our bills on time, and we were able to continue our frequent family vacations. Hiking, camping and canoeing in State and National parks remained our favorite

pastime. Family visits and spending time with loved ones ran a close second. We spent considerable time with both Joan and my families including brothers, sisters, cousins, uncles and aunts. It was a good time for all of us.

In the mid 1980s, Joan and I cashed in a retirement account that we had saved and took the kids to Europe. We rented a recreational vehicle for three weeks and toured Germany, Austria, Italy, Switzerland and France. Some of our friends said they didn't know how we could take all the time we were taking with our family. Our response was that we couldn't imagine not taking the time to spend with family. Having a child with a chronic illness taught us the importance and value of spending time together. It would be an important lesson, made more important and reinforced later in our lives.

All three of our children continued to adapt well to life in Cooperstown as we settled even deeper into the community. In time Joan and I bought the house next to the elementary school. It wasn't too long before our home became the local hang out for all the neighborhood children. It was common for many children of all ages to be gathered at the pool deck in our back yard during the warm summer days. Joan and I enjoyed the status of being the central family community collection point of Cooperstown. To make it even more official, my position as Scoutmaster of the Boy Scout Troop attracted even more children to our home.

Because I was the Scoutmaster, my daughters and Henry (still too young to be a Boy Scout), were able to go on Scouting adventures. As honorary members of our troop, the three children could participate in any trip they pleased. Jennifer and Diana, unable to earn the ranks and merit badges of the Scouting program because they were girls, accomplished as much as any Eagle Scout ever produced by any troop anywhere. By the time Henry was eight years old, he was already a talented backpacker and canoe paddler. He had climbed Mount Marcy, the highest mountain in New York at 5,344' and canoed hundreds of miles on the nearby Susquehanna and

Delaware Rivers. Never did Henry allow his Hemophilia to get in the way of an adventure.

Henry's first trip to Mount Marcy was during an autumn four-day hike with the Boy Scouts. The weather was uncooperative for this October adventure. It was cold and rainy with intermittent snow showers. But I had prepared my Scouts well. They knew how to cope with Mother Nature. They put up their tents so quickly that their gear and sleeping bags stayed dry. While we would have all preferred warmer and dryer weather, we did not allow this inconvenience to dampen our spirits or to spoil our mountain adventure to the high peaks of N.Y.

Accompanying us as a guest on this adventure was a physician friend named Charles Stackhouse from Bassett. Charlie was not yet an experienced backpacker and was unused to the rigors the boys faced on our trips. Charlie was tall, significantly taller than my nearly six foot frame. He had an impressively long stride—well over three feet so even though he was inexperienced, he did rather well on our trek. As luck would have it, on the third day of our hike, Henry lost his footing on a slick bolder and skidded on his buttocks to a hard landing a few feet below in the mud. The impact of the fall jammed his knee. Henry knew immediately that he needed to be transfused. We stopped our small group of hikers about 5 miles from our cars and in the rain, sheltered by ponchos held by fellow hikers, Henry and I prepared his Factorate ™. Charlie watched in amazement as Henry and I went about the extraordinary business of being normal with Hemophilia. Later that day when Henry rejoined the Scouts at the front of the line of hikers, Charlie and I spoke.

"Hank, I figure that my stride here in the mountains is about three feet, which means that for every mile I have to take nearly 1,800 steps. Since we are hiking twenty miles this weekend that means I will be taking about 36,000 steps." Obviously Charlie had been thinking about this.

"I have also noticed that Henry's stride is about one third mine, which means that this weekend he will be taking more than 100,000 steps."

I for one had never thought about it quite like that.

"I just can't believe that Henry isn't complaining..... about anything! It all seems normal to him." Charlie said.

Of course, that was the point. To Henry, this was normal. Hiking in the rain and snow, climbing New York State's highest mountain, taking more than 100,000 steps, getting transfused in the rain were all normal.

To a casual observer Henry looked very much the picture of a perfectly normal, healthy, active young boy. With the exception of a medic alert bracelet that Henry now wore on his wrist, he was most often indistinguishable from the collection of other boys in our lives. On more careful examination, however, he was easily distinguished from the other neighborhood children by the array of his multiple multicolored bruises that seemed always on display. Because he was an active child, he always had some new and unexplained bruises of varying ages and sizes. Most often he did not require any treatment for his bruises. Sometimes a transfusion was necessary to prevent the large and unsightly lumps from becoming unmanageable. Henry often attracted stares and sympathetic looks from perfect strangers in grocery stores or other public venues. Joan and I were certain that we had been branded as child-abusing parents by scores of unknowing and uninformed adults who observed us with our children.

Joan and I learned with experience and a little help from our friends in the pediatric clinic that we could fairly accurately age bruises depending on the color and the condition. A fresh injury was usually dark blue to black in color. As the bruise aged, the color changed to a more golden yellow hue with lighter shades. Coloration was due to the chemical process of the body breaking down the blood and the iron that was trapped in the tissues. It was not at all unusual for the bruises to have a small or medium egg sized lump of calcification or a solid mass in the center that might sometimes take weeks or even longer to resolve. Although unpleasant to look at or to

touch, it was not a dangerous condition since the body was reabsorbing the lost blood.

In addition to the unpleasant appearance of the frequent bruises that Henry sported, his Hemophilia did have more serious consequences. His repeated bleeding into his joints caused a corrosive effect on his ankles and knees. His left knee and his right ankle were significantly affected. It was not unusual for Henry to be confined to a wheel chair or to attend school on crutches as he nursed a bleed in his ankle or knees. In spite of his weakness in those particular joints, Henry continued to be an ardent and skilled backpacker and hiker. When he was older he became one of the Senior Scouts and a Senior Patrol Leader of our Scout troop.

We continued to deal with Henry's Hemophilia in the same straightforward way that we dealt with life. We had learned that Hemophilia was more of an inconvenience than a disability. Henry did not seem even slowed by the fact that his blood did not clot. Eventually we all learned to transfuse him at home. Although any of us could transfuse him, Henry preferred the gentle and loving touch of his mother to the less skillful and less practiced touch of his father and sisters. The transfusion process was not that difficult it was however complex.

[iii] A detailed description of the home infusion or transfusion process is available in the end notes.

With our encouragement, Henry learned that Hemophilia was a treatable disease. He understood that it would be a life long inconvenience, but hopefully not a disability. We had long ago made the decision to infuse Henry aggressively at the first sign of joint injury to prevent his joints from being more seriously affected by the prolonged effect of repeated bleeding. We had heard stories of untreated adult Hemophiliacs and had met some who, confined to wheel chairs, wore knee and leg braces because of repeated bleeding injuries to their joints. We were determined to do everything possible so that our son would walk as an adult.

By the time Henry was ten years old, he had more than three hundred blood transfusions. Most of which were of Cryoprecipitate, made from the pooled blood of perhaps ten donors. As medical technology advanced and treatments continued to change, some of the transfusions were from the much more expensive but easier to use freeze-dried Factorate ™. We did not yet understand the difference. Factorate ™ was made from the pooled blood of 20-60,000 individual blood donors. We were soon to learn the importance of that significant difference.

Something New In the Blood Supply

It was the spring of 1984, after one of Henry's routine medical appointments, when Pedro (Henry's pediatrician) asked to meet with Joan and me. As we sat together on an exam table in one of the pediatric exam rooms, Pedro explained about something new in the blood supply. He reminded us of what we already knew, that Henry was already at risk for developing any number of blood borne diseases. In fact, Henry had already contracted more than one type of hepatitis from his frequent blood transfusions. He would have chronic liver problems for the rest of his life as a result of those transfusions. But now, Pedro explained that the Center for Disease Control in Atlanta had identified a new "bug", most likely a virus that seemed to be transmitted by blood transfusion. It had been called G.R.I.D.S. or Gay Related Immune Deficiency Syndrome because it was first identified in and seemed to be more common to homosexual males. Recent studies, however, showed that it was not just a sexually transmitted disease but a blood borne disease. Because it was no longer just found in homosexual males, the disease had been renamed AIDS or **A**cquired **I**mmune **D**eficiency **S**yndrome.

In April of 1984 the U.S. Department of Health and Human Services announced that a medical researcher named Dr. Robert Gallo claimed to have discovered the virus that caused AIDS.[iv] Of course we had both heard of AIDS as it was being mentioned almost daily in the news. Joan and I were already paying attention to any public discussion of blood borne illnesses, but we had never considered the risk to Henry from this new and terrifying disease.

Pedro went on to explain that there was no test for AIDS. No known cause or treatment existed. To be blunt, there was nothing that we should be doing differently for our son because no one knew about the prevention of this new disease. Pedro just wanted us to be aware that it was one of the many risks that Henry faced as a result of having Hemophilia. He asked us if we had any questions. Luckily, we didn't because he had no answers.

As Joan and I walked out of the hospital still holding hands we said to each other, "Great, another thing to worry about, but nothing to do...."

Just over a year later, in the summer of 1985, Joan and I received a phone call from a nurse practitioner, Diane, at the regional Hemophilia Treatment Center in Syracuse, New York, where Henry went for annual comprehensive Hemophilia check-ups. Diane knew us and Henry. Henry was 11 years old.

Diane explained that there was now a licensed antibody test for the AIDS virus that would tell us if Henry had been exposed to AIDS. The technicians at the center had tested stored samples of Henry's blood and knew the results of the test. She asked us whether we wanted to know whether our son had been exposed to AIDS.

Joan and I asked some questions first.

"Had Henry's blood has already been tested?"

Diane replied, "Yes. Frozen serum samples from October 1983 and August 1984 had been tested."

We continued, "Would a positive test mean that Henry had AIDS?"

"No, but it was an indicator," she replied.

We then asked, "If he had a positive test, would it mean that he would be treated any differently?"

She responded again,

"No. There is no treatment for AIDS."

Once again we posed the question, "If the results of the test should be positive, would there be anything we should do differently?"

Again, the response was "No".

Joan and I decided not to ask the real question that was on all of our minds—the one Diane had called about. Specifically, what was the test result? Was Henry positive for the virus that causes AIDS? Since there was nothing we could do about it we choose to not know if our son had been exposed to or was likely to get AIDS. There was nothing to do.

That was July of 1985. By August, I began to have second thoughts. I felt confident that Henry was not infected with AIDS. He was healthy. It was about time our family got a break! The odds of getting Hemophilia were one in 10,000. What were the chances that Henry would have Hemophilia, Von Willibrands disease and AIDS?

I formulated a plan. I would get the test results. They would be negative. I would find out and tell Joan. Then there would be one less thing to worry about.

On a quiet day at work in the police department I decided to call Diane at the Regional Hemophilia Treatment Center.

"Diane, we have changed our minds. We would like to know the results of Henry's AIDS test."

"OK.", she said. "I will have to look them up as the test results are coded. You do understand that we don't know what a positive result means. We don't know if it means that he will get AIDS or not. It just means that we think he has been exposed to the virus that causes AIDS."

"I understand." I said.

"There is no treatment, and there is nothing you could do differently." she said.

"I understand." I repeated.

"I will call you back." she said.

More than a week went by. Diane never called back.

In early September I called her back. We had all been busy. Diane apologized for not getting back to me. She still did not have the results, but she assured me that she would call back as soon as she got the results. Two more weeks went by.

The third week of September, 1985, I called Diane back. "Diane I want the results. I am willing to hold the phone until you get them. Can I have them now please?"

"Hank, I have them here," she said. "I have not looked at them yet. I will if you want me to. Before I do, I want you to know that there is nothing you can do differently. There is no treatment. If the result is positive, it does not mean that Henry has or that he will get AIDS. We don't know what a positive result means. All we can say is that he has been exposed to the AIDS virus." She paused and then asked, "Are you sure you want the results?'

"Diane, I know, I understand. Give me the test results!" I said firmly.

"He is positive." she said.

I couldn't breathe. I couldn't talk. Tears filled my eyes. This was impossible. This was not the plan. After what seemed like an impossibly long time, Diane's voice registered in my ears from the other end of the phone.

"Are you alright?" she asked.

"No." I said weakly, trying unsuccessfully to choke back the tears.

"Do you want to talk?" she asked.

"No." I said.

"Call me back later when you want to talk." she said.

I hung up the phone, regained my composure and dried my tears. I then left my office. Unobserved by anyone, I walked to my police car. This was stupid. Incredibly stupid! There was nothing to do. There was no treatment. The test didn't mean anything. He might have the virus. He might not. It only meant that he had been exposed to the virus. It didn't mean anything except that Henry had been exposed to the AIDS virus. I repeated it again and again to try to convince myself that nothing had changed.

Once in the police car I drove away from Cooperstown, away from my wife, my children, and my home. I couldn't face my family. This was not the plan. I was going to be a hero. I was going to tell Joan the good news that Henry had not been exposed to the AIDS virus. But now, I knew that Henry had been exposed. I also knew that people with AIDS were on average living less than two years. Henry was twelve years old!

Those early years in the AIDS epidemic were an especially terrifying time. If people knew that Henry was exposed to AIDS, he would be a pariah, like Ryan White, the Hemophiliac of Kokomo, Indiana. Henry would be excluded from school. We would all be subject to the real and imaginary fears of a community that had not yet come to grips with this growing epidemic. We all risked being excluded from the community we loved. We risked being shunned by everyone we knew. Henry, Jennifer, Diana, Joan and I lived in a small rural community where everyone knew everyone. If any one person knew our secret, everyone would know in short order. There is no such thing as a secret in a small town. Not only did Henry have a potentially fatal illness, he had an illness that would have serious implications for our family.

I couldn't tell Joan and I couldn't go home.

Fortunately for me, I had an open police investigation in New Jersey some 200 miles to the south. It was a perfect excuse. I called my dispatcher on the radio when I was far from home en route to the investigation. I asked him to tell my

wife that I would be gone for a few days. It was easier to not be home. I couldn't face Joan. I couldn't face my son.

Three days later after taking the time to cry myself out, I returned home. At least now I would be able face Joan and the children without crying. Now, I had a plan.

In the fall of 1985 and early in 1986 I was completely consumed with learning about AIDS. I subscribed to *JAMA* (*Journal of the American Medical Society*), to *Lancet* (British Medical Society's journal) and to the *MMWR* (*The United States Center for Disease Control Morbidity and Mortality Weekly Report*). I read every word of every article about AIDS and the frenzied research into this new and devastating terrifying disease.

In June of 1986, I found a researcher at the State University of New York at Stonybrook who was doing research with AIDS patients. I anonymously spoke with him about Henry. He was willing to try to enter Henry into an experimental drug treatment protocol if Henry could pass for 18. He explained to me that he was researching an experimental drug for adults over the age of eighteen. He suggested that I send him a photograph of my "eighteen year old son" and he would consider entering Henry in a compassionate use drug protocol. Because people with AIDS had less than a two year life expectancy and tended to be desperate, it seemed compassionate to experiment on them.

I was desperate. Joan still did not know that our son had tested positive for exposure to the AIDS virus. If Henry were going to be treated in an experimental program, Joan would have to know. Then we would need to tell Henry.

A Family Secret

It was July 4, 1986. Joan and I were driving to visit her parents. Our kids were sleeping in the back of the car as we drove. I began, "Honey, do you remember last year when Diane asked us if we wanted to know whether Henry had been exposed to AIDS and that we decided that we did not want to know?" I carefully phrased my question.

"Yes." Joan said, her voice cracking with instant emotion. She knew that this was not going to be good.

"Well, if there were an experimental treatment for AIDS now, and if he tested positive, for the virus, would you want to know?" I asked.

Joan was quiet for what seemed like a long time. "You bastard! How long have you known?"

"Since September," I said.

I tried to explain, but it was no use. Joan was furious. And she was right. I should have told her. In my defense, I tried to explain that there was nothing to do. I did not want her to agonize as I had been agonizing with the terrible news and the reality that there was nothing to do about it. But now, now for the first time in the year since I had found out, there was some hope.

I explained to her that I had found an experimental treatment in which we might be able to enroll Henry. I then provided the details.

I think she understood. I don't think she will ever forgive me. I knew for ten months that our son had been exposed to AIDS without telling her. For ten months, I had gotten to treat Henry differently. I knew how important every day was. I should have told her. I wish now that I had.

Joan, always the practical one, shifted her anger at my deception to her need to help Henry. She immediately focused on what needed to be done. There was no going back to change the secret I had kept.

Now that we both knew the secret, we both agreed that we would have to be very careful with whom we spoke about Henry's exposure to AIDS. Together, still in the car, we began to draft our plan.

We decided to share our news with a few select people —Joan's mother, Rosemary; Joan's sister, Pat; and her husband, Bob Maul. We correctly believed that we could trust them with the secret. We were not so sure about all of our family and friends, but we knew we could trust Pat and Bob as our families were very close. Joan was godmother to their oldest daughter Maureen. We had vacationed with Pat and Bob. And, like Joan, Pat was a carrier for Hemophilia although none of their three children carried the gene. In the unplanned and unwanted event that Henry's AIDS exposure should ever become public, Joan and I made plans for Jennifer and Diana to live with Pat and Bob at their home in New Jersey, near New York City. We were worried about what our community or any community might do.

It was a strange time. People were afraid of AIDS. People were afraid of AIDS patients. It was in1986 when the mother of Ricky, Randy and Robert Ray, three Hemophilic boys found out that her sons were infected with the AIDS virus. Needing guidance and solace, she paid a call to her Arcadia, Florida church pastor. Upon hearing her story, the pastor asked her not to return to his church. The boys were excluded from attending school in De Soto County, Florida. To escape this discrimination, they fled to Alabama. But there too, the word got out that the boys were AIDS patients. Finally, they returned to Arcadia where they would win a court battle in 1987 forcing the school to take the boys. The Ray family home was burned down in what was suspected but never proven to be arson.

People were frightened of AIDS, and frightened people do strange and terrible things. People were not only afraid of AIDS

but this fear generalized to anyone who was at high risk for AIDS. Gays, Hemophiliacs, and Haitians were all singled out for discrimination because all three groups had been identified as high risk for AIDS.

As a culture, we were terrified. As a family, we were terrified. Not only did Henry have a potentially fatal illness, he also had an illness that must be kept secret. So aside from the few members of the family, we agreed to tell no one else. It simply was not safe to trust people with our secret. If a doctor, a nurse or a secretary told a spouse or a partner, the secret would be no longer. Joan and I decided that we would not even tell our family doctor in Cooperstown. Although Diane at the Regional Treatment Center in Syracuse knew our secret, she was familiar with the required confidentiality standards. Furthermore, she lived far enough away and did not even know where we lived. We trusted Diane.

To begin the process of getting Henry into the experimental drug program we needed a photo of our "18" year old son. Joan and I dressed Henry in a suit jacket with a dress shirt and tie. He was tall and thin for his age. Dressed in a suit he looked a little more like an adult, but only a little. Using an eyebrow pencil, we even drew a mustache on his face. There was no way. He looked like a twelve year old boy in a suit with an eyebrow pencil, drawn on mustache.

We didn't tell Henry what this was about. We tried to make a game out of the picture. It was rather funny as we joked about it, telling him it was a gag photograph. We wanted to see if we could get him to look like an adult. It would have been truly funny if it were not a life and death situation.

There was no way Henry would pass for eighteen. The experimental treatment plan was out. It wouldn't work. There was no compassionate treatment protocol for experimental children.

If we were going to aggressively pursue options, Henry needed to know that he was at risk for contracting AIDS. Henry was smart. He knew that being a Hemophiliac put him at risk for blood borne diseases. He had heard and read enough about AIDS that he, at least, suspected this was a possibility. Joan and I thought about how to tell him. We choose our words carefully. We explained that although he tested positive for AIDS exposure, we were unsure what it meant. It did not necessarily mean that he would get AIDS but only that he had been exposed to AIDS. We told him we did not think he would get AIDS and that we all needed to be positive and act as though he was not going to get sick. We were just going to take precautions and investigate any alternative treatments.

Henry asked us again if we thought he would get AIDS. We both lied and said "no". I think he knew we were lying. Henry asked us not to tell Jennifer and Diana about his positive test. He did not want his sisters treating him like he was going to die.

Joan and I convinced Henry that Jennifer and Diana needed to know about his positive test. We explained to him that it was not fair to the girls to keep such an important secret from them. Reluctantly, Henry agreed. In August of 1986, we had a family secret.

For the first time in nearly a year I was not living alone with a secret. Keeping a secret can be hard. Keeping a secret from the people you love is even more difficult. Now that my loved ones knew the secret, my personal burden was lifted. But I had mixed feelings because, although we now shared the secret among ourselves, we also shared the burden of keeping it to ourselves.

It was unfair for us to have to live with this secret!

High Hopes

In August of 1986 Henry and I volunteered to work together at a special camp for Hemophiliacs named High Hopes. I was the Camp Director. Henry was too young to really be on the camp staff but nonetheless he served as my assistant. The camp was the idea of Diane Groth, the nurse from the Regional Hemophilia Treatment Center and Kris Richardson, a mother of a child a little younger than Henry. Diane and Kris wanted to have the Hemophiliac children in our treatment area have the experience of going to summer camp. Most summer camps were ill-equipped and reluctant to handle these special needs children. Camp was only one week long. Together Henry and I with other adult volunteers including Henry's Uncle Bob Siana and Aunt Donna O'Donnell, my father in law Thomas O'Donnell and my parents Hank and Irma taught the children to climb trees, ride bikes, swim, rappel down ropes, and build towers by lashing trees and branches together. Bob Siana taught Indian Lore and slept in the camp teepee with the kids who called him Indian Bob. Donna taught crafts in the craft lodge, and my parents served as general supervision. It was high adventure for the Hemophiliacs who, by and large, were leading sheltered lives under the watchful and sometime over protective eyes of their parents and healthcare providers. It was a great week for the kids, for Henry, and for me.

For the first time in his life Henry met other Hemophiliacs. Twenty of them attended camp. He was amazed. His whole life he knew that he had Hemophilia. He knew there were other people with Hemophilia, but he had never met any. It was comforting for him to know that other people had the same disease. His bunk mate was Michael. I had assigned the two boys to the same room as they were about the same age. On our first night at camp, I stood outside the open door of their room, listening to them talk after lights out. I was eavesdropping.

"Are your parents really weird?" asked Michael.

"Yeah." said Henry, "Like always asking where did you get that bruise?"

"Right, like we are going to know where we got some bruise." Michael agreed.

It was fascinating to me to witness the instant bonding and the joy in discovering that they were not alone in their disease or in the world.

Because Hemophiliacs have so many medical issues, Camp High Hopes had a resident camp doctor. A volunteer like the rest of us, Doctor Bob and Donna taught the children to build and to fly rockets. Each child built a minimum of two rockets. Then on a designated afternoon during the week we had rocket day. Each of the twenty children and a few of the adults sent their rockets soaring high into the sky.

Estes ™ rockets can go more than 1,000 feet in the air. They are so fast and fly so high that they are nearly invisible when they reach the top of the flight path. At the end of the engine thrust, a small explosive charge fires at the top of the rocket pushing a waiting folded parachute out of the nose cone. The rocket is gently lowered back to earth. At least that is what is supposed to happen. We had some rockets that deviated from the plan. A few of the rockets failed to fire the parachute charge which caused the rockets to return to earth at terminal velocity. Terminal velocity for a rocket falling from 1,000 feet is VERY fast. Fortunately failed parachutes were very rare. The rockets that did fall without their parachutes would land nose first several inches deep in the lawn. We were lucky that no one was hit by the incoming rockets.

Rocket day was a great success. We flew rockets until all our rocket engines were gone. Thankfully, most of the parachutes did deploy. Many of the slowly descending rockets were caught by the wind and drifted into nearby trees. On our way out of camp, we couldn't help but notice that the trees appeared to have already been decorated for a very early Christmas celebration. These Christmas ornaments were rockets dangling from parachutes!

Because all the children at High Hopes had Hemophilia, there was a high probability that many of the children might be HIV positive. Some were further along with their illness than Henry. During the second year of the camp, some of the children were starting to get sick. They were coming down with illnesses that healthy children didn't normally get. Joan and I agreed that we did not want Henry around children who were getting AIDS. We were not only afraid of AIDS but we did not want him to see the terrible reality. Some of these children might soon die. We did not want our son to be forced to confront his mortality by watching his friends become ill and die. We did not want this scenario to be Henry's vision for his own future. It was our last year at High Hopes. Much to the credit of Diane Groth and Kris Richardson, the one week long specialty camp for Hemophiliacs continued. It just did not continue with us. I regretted not feeling strong enough to be able to continue as the camp director. I just did not have the strength to live with my son's illness and the illness and death of his friends, children that I loved and worked with as well.

9. The High Hopes Gang

By fall, lots of things were going on. I resigned my position as Police Chief and accepted a new position at Bassett Healthcare as Director of Security. My new job paid nearly the same salary and provided me with a much more predictable schedule and more time at home. It was important to both Joan and to me that we spend more time together as a family.

Because we were not willing to divulge Henry's condition locally, Joan and I decided to seek medical help for Henry elsewhere. We found a physician who was doing early work with AIDS patients, Dr. Fred Siegel. He was associated with Long Island Jewish Medical Center 200 miles away. We thought that would be perfect. There in the suburbs of New York City, a twelve year old boy seeking anonymous treatment for AIDS infection would be less likely to attract much attention. Even if he did attract attention, no one would know who we were.

With great apprehension we took Henry to his first appointment at Long Island Jewish Hospital. We watched anxiously as a nurse with tears in her eyes and trembling hands drew his blood to confirm the results of the test that had been done anonymously in Syracuse years before. The nurse, a professional caring and competent provider, had never drawn blood from a child with AIDS before. It was hard on her. AIDS was not a discriminating disease. It would kill anyone. The nurse knew it. She just had never seen it before in a patient so young. It was so unfair to Henry and to our family. We could see her concern and her empathy. I thought grimly that Henry would not likely be the youngest or the last child she would meet with AIDS.

The immediate future saw a frenzy of visits to Dr. Siegel and the Long Island Jewish Hospital. Henry underwent test after test to try to determine the risk and the rate of his potential AIDS infection. In those early days of the epidemic, no test for the AIDS virus existed. Rather the use of surrogate tests helped to measure the quality of the immune system and the progression of the disease. The combination of a low white cell count and a case defining illness moved one from the classification of being infected with the AIDS virus to having

AIDS. Henry was not yet an AIDS patient, he was only HIV Positive.

At that time, to be classified as an AIDS patient a patient's white blood cell count had to be extraordinarily low, and the patient also had to have one of the listed infections that healthy normal people almost never get. A large number of these rare infections including pneumocisitis pneumonia, Kaposi's sarcoma and "Thrush", an atypical fungal infection, were classified as "case defining" illnesses.

Our plan was to keep Henry from ever progressing to "full blown" AIDS. He took a regimen of vitamins, dietary supplements, and some broad spectrum prescription antibiotics. We were committed as a family to healthy living.

Mega doses of vitamins, health foods, macrobiotic diets, preservative free foods, vegetables, outdoors living, lots of water, exercise, and a positive mental attitude were high on our to do list. We experimented with everything we could think of. In the final analysis all of our efforts seemed to be in vain. Henry's counts kept getting lower. It was very frustrating.

In our desperate search for something to do, we occasionally stumbled on something that gave us hope, even if only briefly. One time I read a newspaper account of a pharmacist in the Washington, D.C. area who was claiming remarkable results with AIDS patients. I tracked him down by phone at his pharmacy. After speaking with him I convinced myself that he was a real pharmacist and that he was really working with AIDS patients. He claimed that by using a strict regimen of vitamins and macrobiotic diet, he was able to keep blood counts of the AIDS patients from getting lower.

There seemed to be some hope when the pharmacist said, "None of the patients I am working with have progressed in their disease since we started my treatment."

It was something. At last there was something we could do. There was a glimmer of hope. Almost any action seemed better than no action. After describing Henry, including his weight and age, I gave the pharmacist my credit card number and authorized about three hundred dollars of vitamins and supplements. The pharmacist promised to ship the supplements that would offer the best chance of delaying the disease. It sounded far fetched, but it was the first thing we had ever heard of that even offered to impede the progress of the disease.

A few days later a parcel post box arrived in the promised brown paper wrapper. It contained a large assortment of vitamins, minerals, food supplements and food additives and a book with recipes for macrobiotic meals.

We attempted to follow the enclosed strict schedule religiously. It required an exact schedule of pills and beverages mixed with supplements on a four and six hour regimen. We set alarm clocks to alert us to the schedule. Joan and I took turns waking our sleepy eleven year old son from what should have been restful sleep to the strict schedule of many pills and awful smelling beverages. We and Henry lasted nearly a week on the schedule. Then we lapsed into a saner but less sincere attempt to follow the strict schedule sent by our friend the pharmacist.

But that wasn't the end of the macrobiotic maneuvers. Joan decided to experiment with macrobiotic cooking. A macrobiotic diet derives its name from the Greek word "macro" for large or long and "bios" for life, and is most often a dietary regimen which involves eating whole grained foods supplemented with other foods such as vegetables and beans while avoiding the use of highly processed or refined foods. The diet book also recommended that food be thoroughly chewed before being swallowed. It sounded reasonable.

There were two recipes from the cookbook that caught Joan's eye. The first recipe was for pizza. Our family loves pizza. Our favorite pizza came from Sal's Pizzeria on Main Street in Cooperstown. Although 200 miles from New York

City, Sal and his brother John had perfected the art of making New York pizza! Their secret combination of properly blended and mixed herbs, spices, flour, oils, tomatoes and cheese- hot from the large ovens was oh so good. How could she go wrong with a macrobiotic pizza made from whole wheat flour and soy protein?

It was terrible! We all love Joan, but love and loyalty this time were not enough. We could not bear to eat the imitation pizza concoction she fashioned after the macrobiotic cookbook recipe. Even the dog, Nanda, who ate nearly everything, refused to give the pizza a second try. Instead we escaped to Sal's for a return to pizza sanity. We never told Sal how we had nearly strayed. We did not want him to know that there was no competition. (I ordered mine with anchovies!)

The end of the experiment came when Joan discussed her planned second macrobiotic dish. Jennifer broke the news as quickly as the suggestion was made. "*Mom, none of us are going to eat carp soup.*"

So ended our first, but not the last, unsuccessful AIDS treatment regimen, many more would follow. We were always on the look out for something we could do. We were desperate for action. Almost anything that was an affirmative plan was better than waiting with the promise of nothing.

In time, drugs were developed that would later become the anti retroviral regimen that is in use today. Henry was one of the first patients involved in the experimental protocols that lead to the modern treatment options.

It seemed that no matter what we did, Henry's immune system went steadily down. His CD4 count, which started at more than 400 cells per deciliter of blood, (that was less than half what normal should have been,) fell steadily. By 1988, his CD4 cells numbered in the single digits. Henry named half of his CD4 cells with boy's names and half with girl's names. He explained that this way he could explain any hoped for

population increase through the normal flirtation and mingling of his CD4 cells. Although his CD4 count continued to fall, his sense of humor remained high. Doctors, nurses and lab technicians were all amused at his sense of humor.

Henry was active and in spite of lab tests to the contrary, he appeared to be healthy. He continued backpacking and hiking. In those years as his body and his immune system were beginning to fail him, he twice hiked with our family and Boy Scouts through the Grand Canyon. One trip we hiked rim to rim to rim. We descended from the south rim of the Canyon nearly a mile down to the Colorado River. Then we climbed up to the north rim. Then returning again to the river, we hiked back to the south rim. This hike of more than 50 miles through the desert required wearing a backpack and carrying food and water for five days. Although he was skinny, he seemed fit. To all outward appearances he denied the struggle that was occurring beneath the surface with his immune system. By 1989, Henry had a CD4 count of zero. This meant that he had no white cells to fight infection. It seemed that it was a matter of time until he would progress to full-blown AIDS. Again Henry's sense of humor came through. He explained to his doctor and nurses that although it looked like his CD4 count was zero, the truth was that Aloysius, Lupe, and Carmen were all hiding. They, his named CD4 cells, had survived and were hiding from the AIDS virus.

We continued our trips to Long Island Jewish Medical Center and were regulars in the clinic of Dr. Siegel. Henry continued his AIDS treatment as an anonymous patient but continued to receive his routine Hemophilia care at Bassett Healthcare. Once Henry's then hematologist in Cooperstown, a wonderful and caring physician named George Davignon, asked me if I thought we should have Henry tested to see if he were positive for the AIDS virus.

"If you tested Henry and his test was positive would you put it in his chart?" I asked?

"Yes, of course," George replied.

"Would your secretary do that or would you?" I asked for clarification already knowing the answer.

"My secretary." he replied.

"Then we are not interested in having Henry tested for AIDS." I explained.

George suspected, and I thought that he knew, why we did not want to have Henry tested for AIDS. Although both George and his secretary could be trusted, there were also a medical records clerk, a transcriptionist, a phlebotomist, a lab technician, a pharmacist, a nurse's aid, a housekeeper, a dietician and a host of other people who might have reason to have access to Henry's chart. One or more of them might have children in school with Henry. Each of them was, of course, required to keep medical information confidential, but people were still frightened of AIDS and scared people are often not rational.

"Is there anything you would do differently if you knew Henry was positive for AIDS?" I asked George.

"No," he replied. "I would just watch him more closely."

"We are watching him very closely." I said. I knew that George knew that we knew. We just were not going to talk about it.

During the spring of 1990, I contacted the Make-A-Wish Foundation. The Make-A-Wish Foundation has a mission to create hope and happiness for children with a life-threatening illness. Henry certainly qualified, and I thought a little more hope and happiness might be helpful. Make-A-Wish is the largest wish granting organization in the world. Today it has locations in nearly 30 countries and on five continents. Make-A-Wish America and the international branch have granted more than 187,000 wishes around the world since the early 1980's.

After the initial contact and with assurance that Make-A-Wish would protect our confidential status about being HIV positive, I introduced Henry to a wish granter, whose name was Kathy Grossman. A wish granter is a volunteer whose job is to grant wishes to the sick children. After interviewing Henry about his Hemophilia and receiving certification from his treating physician about his bleeding disorder, Make-A- Wish accepted Henry as a client. Henry was eligible to be considered for Make-A-Wish by virtue of both his Hemophilia and by his HIV infection.

Henry's Make-A-Wish, wish was to go to Switzerland to climb on the Matterhorn. The Matterhorn is the quintessential mountain. It is the most easily recognizable mountain in the world. Cut from a single block of granite towering more than 14,000 feet into the Swiss Alpine sky, the mountain is what most people see when they imagine a mountain. Henry, who had learned to mountain climb as a Boy Scout had dreamed of visiting it since I told him stories about my visit to the mountain when I was a college student. He was just a small child when we had watched the Disney movie *Third Man on The Mountain*. I had given him a copy of the true story by Edward Whymper "*Scrambles Amongst the Alps*" of the first ascent of the Matterhorn. The Matterhorn was one of Henry's life list goals. We never thought he would see it, let alone attempt a climb. Climbing the Matterhorn was certainly an unusual and it seemed to us an impossible request.

Kathy Grossman, our wish granter, made Henry's wish come true. During the summer of 1990, when Henry was 16 years old the Make-A-Wish foundation offered to send him to Switzerland. What a great opportunity for Henry and for the whole family!! Joan and I asked to build a family trip at our own expense around Henry's adventure. With the consent of the Make-A-Wish Foundation, we were all able to enjoy a three week trip to Germany and Switzerland.

We visited family in my mother's home town of Weinsberg in southern Germany, and while there Henry collected the most amazing souvenir of the trip imaginable. Like many boys are, Henry was fascinated with edged weapons. Knives and swords

held a special interest for him. While walking through the very old German town of Schwabish Hall where my mother had gone to school, Henry found a shop that was selling beautiful replica Japanese samurai swords. The swords were made right there in Schwabish Hall. Henry so much wanted to own the sword. It was the only souvenir he wanted or brought home from the entire trip.

After visiting my mother's family we moved on to Zermatt, Switzerland, the home of the Matterhorn. The entire family played on the mountain. Diana, Henry and I even climbed to Hornli Hut high on the slopes of the Matterhorn. The three of us camped in the climbers' hut on Hornli Ridge and hoped to finish the 4'000 remaining feet to the summit on the next day. We hired guides and rented gear. We went to bed early that night knowing that, if we were to climb the Matterhorn, we would have to leave very early the next morning. As the sun rose bright in the crisp clear alpine air, I knew that we had slept too late to climb.

I snuck out of the bunk room leaving Henry and Diana still asleep and went to the larger room. Our guides were just finishing their morning coffee. The guides explained that had been an ice storm during the night making the mountain off limits for climbing that day. The Matterhorn is a serious mountain and each year people die trying to climb it. Going higher was impossible. The mountain shone like a bright diamond glinting in the sun under a coating of fresh ice. We could climb no higher. Our window of opportunity to climb was gone. Henry, Diana and I headed back down the mountain. Diana was in the lead. The cold mountain and the warmer moist air at the lower altitude caused a thick fog and at one point we took a wrong turn and started to go down the wrong trail. We were nearly in Italy before Diana realized our error and returned up the mountain and turned back into Switzerland. Diana who is normally a fast hiker seemed slower than usual and it wasn't until hours later that I discovered the reason for her lack of speed. Unbeknownst to me, Diana had collected about 40 pounds of rocks from the mountain to take

home as her souvenir. We returned to Zermatt where Joan and Jennifer had maintained a concerned vigil in our apartment in town. Although we never reached the summit, we were higher physically and mentally than we had ever imagined we would be. We were above the clouds.

I often view mountain climbing as a metaphor for our lives as a family. Together as a family we were experiencing events, and challenges and opportunities that few others could even imagine. Mountain climbing is not just about getting to the top. It is about the journey, the adventure and the experience. Life is the same way. It is about the journey, the adventure and the experience and not just the destination.

10. Henry and Diana on the Matterhorn

As the summer drew to a close so did our family trip to Switzerland supported by Make- A- Wish Foundation. It was a wonderful trip. Make-A-Wish had made one of Henry's (and our) lifetime dreams come true. We returned to the United States at the end of August. Henry was ready to return to his studies. He was seventeen years old and a senior in high school.

His unusual life was about to change, yet again.

AIDS

On November third of 1990 in his senior year, Joan and I were getting ready for work when Henry came downstairs to our bathroom. It was our wedding anniversary. We had been married for twenty two years.

"Mom, Dad, I can't swallow," he said. He looked a little frightened and very tired.

"Let's take a look." Joan said. We examined our son together. He opened his mouth and stuck out his tongue. The inside of his mouth and throat was coated with a fine but thick and lush white covering of fungus called "Thrush". Joan and I both knew what it meant. Henry had an opportunistic infection. Healthy people do not get "Thrush" in their mouth. "Thrush" was a common vaginal fungal infection for women, but oral "Thrush" was not common. It was a case defining illness for people with AIDS. With a low CD4 count, it meant Henry had AIDS.

We took Henry to the emergency room of Bassett Healthcare. The on-call doctor examined him. With a look of surprise but as calmly as if he were announcing the diagnosis of a cold, the doctor said, "Henry, you have AIDS."

Our family secret was out. Henry was now not only an AIDS patient; he was to be known as an AIDS patient. We lived in a small community; both Joan and I worked at the hospital where he was being treated. We thought it would just be a matter of time before his secret was no longer.

The doctor prescribed some common anti fungal medications to treat the "Thrush" and made some follow up appointments to more closely monitor his condition. Henry was quiet and melancholy for much of the rest of November. He had always known the risk of having AIDS, but somehow it was different having heard the words. He was 17 years old and now the prospect of graduating from high school was a bit

more remote. At that time AIDS patients— those with full blown AIDS—were surviving about two years. Henry had no immune system left. His CD4 count had been zero for more than a year. It was not unreasonable to expect that his progression through the variety of potential fatal opportunistic infections would be rapid. He had every reason to be depressed.

Jennifer and Diana returned from their respective colleges in mid December to spend the winter Christmas holiday with us in Cooperstown. One day in an effort to cheer Henry up, Jennifer said, "Henry, you don't have to keep it secret anymore. You could always go on Oprah and tell the world that you have AIDS."

Little did we know then that words Jena spoke in jest were being seriously contemplated by Henry who had kept his secret as long as he could. In late December, Henry decided that having a fatal illness was a serious enough fate that keeping it secret should not be a requirement of his life. Henry decided he wanted to tell the world about his condition.

Henry was already a Life Scout, the rank in Boy Scouts right before Eagle. He had completed more than the requisite twenty-one merit badges required to become an Eagle Scout, but he had not yet identified his Eagle Scout project.

In order to be an Eagle Scout, a young man is required to not only earn the required number of merit badges but must also do a project that is a service to his community and that demonstrates leadership. It is often the most difficult part of becoming an Eagle Scout. Henry decided that his project would be to promote AIDS education by telling the world that he had AIDS. Perhaps, by being an atypical AIDS patient, he might teach a lesson in compassion and understanding, a lesson in acceptance and tolerance. He discussed his idea with his sisters before approaching Joan and me. He told us that he thought that he would first reveal his illness to his classmates at school. Then he would hold a press conference and tell the world.

Together as a family we discussed the potential ramifications. Jennifer was still in school and was going to be 400 miles away at American University in Washington, D.C. Diana was going to be 400 miles away in the other direction at the College of the Atlantic in Bar Harbor, Maine. Both girls might be affected by Henry's decision less directly because of the distance from our home. The whole family could be rejected by our community, by any community. Henry might be ostracized at school. As we discussed the potential ramifications, we decided that perhaps this would be our chance to find out who our friends really were. Joan and I agreed that, when one of your children, your only son, has a fatal illness, how much worse can life get? We were willing to take the risk.

December and January were spent planning. I met many times with Superintendent of Schools, Douglas Bradshaw. Doug and I began our conversations by talking about the legal requirements and ramifications of a hypothetical high school student with AIDS being identified in the Cooperstown Central School System. Doug was smart. He knew that discrimination against AIDS patients, for any reason, was not only illegal but immoral. Our hypothetical discussions became real and before long Doug spoke with Henry. I think both Doug and Henry were impressed each with the other. Doug was surprised and favorably influenced by a seventeen year old student who had kept a potentially fatal illness secret for much of his life. Henry was impressed that he had a supportive ally in telling his school and community about his infection with AIDS.

Joan and I had already begun telling our family. We had been dropping hints for several years that Henry was at risk of contracting HIV/AIDS as a result of his frequent blood transfusions. We had both already made the observation that blood is really thicker than water. We had family members who, early in the AIDS epidemic, were vocal about the idea of excluding AIDS patients from the general population. Some said that they believed that HIV/AIDS was the result of the wrath of God visited on people whose lifestyle contributed to

their illness. But by the time we revealed the secret, every one of our family members embraced us both literally and figuratively. All of our family was affected, some more profoundly than others. Joan's sister, Kathleen and my brother Steven both quit their jobs and moved to Cooperstown so they could live near us to support us during the coming trials. It was good to have people who we could depend on if we needed help, and we were sure we would need that help!

A Secret No More

In December, after Henry had made the decision to reveal his secret, Joan and I decided to test the community reaction. We thought that we should try a small-scale experiment. We would select one family and share the secret with them to see the reaction. We selected Paul and Carol Bedworth. Paul was a friend who was also one of the scoutmasters for our Boy Scout troop. Carol worked in the laboratory with Joan and had a scientific mind. Paul and Carol had both traveled with us on our scouting trips. Michael, their oldest son, was one of Henry's best friends.

We invited Paul and Carol over for dinner on a Sunday evening. As Henry watched TV in the basement recreation room, Joan and I, with carefully chosen words, first questioned Paul and Carol to probe about their feelings about AIDS. Then we revealed our dilemma. Paul and Carol were truly concerned about Henry first; us second, and were completely unworried about any personal risk. They were smart. They knew that under normal circumstances Henry presented no risk to them or to anyone they knew. There are only three ways you can get AIDS. You could you could be born to a mother with AIDS; you could have sex with a person with AIDS; or you could have another type of blood or bodily fluid exchange with someone who has AIDS. Paul and Carol were great, they understood. They would number among our true friends.

Paul and Carol got ready to leave our home through the basement recreation room where Henry was watching television. Henry knew that we were going to tell Paul and Carol that he was HIV positive and that he had AIDS. As Henry rose to say goodbye, he extended his arm and offered his hand to Paul. Rather than shaking Henry's hand, Paul, a big man, drew Henry into his arms and with an unrelenting bear hug said, "We are with you!" Paul and Carol left without saying anything else. Henry was pleased and shocked.

Paul and Carol had been shocked as well. They knew that Henry had Hemophilia but somehow they had ignored the information to which that they and the rest of the world had been exposed. Somehow they had convinced themselves that Henry was not affected by the AIDS epidemic. Somehow, they and many others had assumed that the AIDS virus had somehow missed Henry. We thought that most of the people in Cooperstown who knew even less about Hemophilia and AIDS than Paul and Carol would have been in exactly the same mind set. Cooperstown did not suspect that one of its sons, our son had AIDS.

In February of 1992, during our winter school recess, our Scout Troop which included not just Boy Scouts but Explorers, or Venture Scouts, boys and girls ages 11-18, took a trip to the Florida Everglades. Joan and I were both leaders of the coed Scout group. Fifty-four of us camped on houseboats, canoed the backcountry and explored the waterways of Everglades National Park one of the Nation's most beautiful and treasured National Parks. Our group swam (perhaps unwisely) in the Shark River and camped on the Gulf of Mexico, eating the fish we caught, telling stories, and sharing the starlit skies with each other and hordes of mosquitoes. We looked at thousands of birds, dozens of porpoises, a few alligators, and even one crocodile during our explorations. We ended the trip by camping at Long Key State Park in Florida Keys. From there we drove to Key West and joined other tourists in the celebration of the sunset that occurs there nightly on Mallory Pier.

Then we returned from Miami to New York to end our trip by riding the rails of Amtrak for the 30 plus hour trip home. During that trip Henry met with the adult leaders of the Scout troop including Paul Bedworth in the back of the Amtrak car. Henry revealed to them that he had AIDS. He continued by relating his plan to do an AIDS education project to complete his final requirement to become an Eagle Scout. He explained that he would be holding a press conference to tell the world his secret shortly after this trip ended.

Following Paul's model the rest of the Scout group was unanimous in its support of Henry and his project. They had all known Henry for the six plus years that he was a member of the Scout Troop. They had been with him on camping trips when he had been infused with freeze dried blood products for his Hemophilia. They had seen him on crutches or in a wheel chair. Some of them suspected that he was at risk for contracting AIDS. All of them supported him. The only question that any of them asked was how they as a group or as individuals could help Henry with his project.

Initially, in the train Joan and I avoided the discussion. We knew that this was Henry's project, and Henry needed to do it. We sat together in the front of the Amtrak car. One at a time, each of the adult leaders found us. In silence, some with tears in their eyes, they embraced us. Some had more than a suspicion. One of our family's best friends in scouting and in the community was Gerry Bers. Gerry was also our family dentist. Several years prior to this time Gerry and I had talked about the hypothetical risk of a Hemophiliac having AIDS. I knew that Gerry was using the standard "universal precautions," which would prevent the spread of any blood or bodily fluid during dental procedures. I suspected, although he never said anything that Gerry knew. That day, on the trip home on the train, speaking to Joan and me, Gerry said, "You should have asked for help sooner." Gerry's sons, Jonas and Jed were in our troop. They were friends of Henry. He knew that there was no risk of AIDS infection from Henry to his own children.

The first week of March of 1991 was filled with activity. We had deliberately waited until the last minute to plan many of the things we needed to work out for fear of word leaking out of Henry's project. I met with the public relations staff at Bassett Healthcare. The public relations director, Mike Stein, called on two of his staff assistants to help us. Mike, Marianne Bez, Jane Schlesser, Henry, and I planned the most important part of the revelation, the news conference. It was wonderful

working with people who were not only professional but who were compassionate and supportive.

Mike, Marianne and Jane knew Henry and our family. There are many advantages to living in a small community. Perhaps the advantages would outweigh the disadvantages. Together they offered recommendations and details on how we could most effectively communicate our message in a non threatening manner that would improve the chances of our community supporting us and not rejecting us. With their help, we decided to hold the press conference at the Boy Scout Service Center in Oneonta. That was about 25 miles from our home and would insulate us from inquiring minds who might want to know where we lived. With the advice of our public relations consultants, we decided to hold the press conference on a Friday morning. The story would make the television news on Friday evening and the print media on Saturday. Sunday, a normal day off, would allow people to absorb the information. By Monday hopefully Henry having AIDS could be old news.

Henry's planned on telling his fellow students at the school. His educational program would begin with those who knew him the best. Wednesday preceding the Friday announcement, Joan and I met with the school board to discuss a hypothetical student with AIDS. Superintendent Bradshaw's secretary and administrative assistant, Darlene Bennett, ushered us into the meeting. Darlene had tears in her eyes and was biting her lower lip. I was sure that Doug Bradshaw had told her what was going on and she empathized. From her look I knew that she shared our anxiety and our worst fears. Doug explained to the Board that this was not a crisis and that he was working with physicians and the school health officer to insure that the law was followed. He reported that a still unidentified student with AIDS had come forward and wanted to tell his classmates about his illness. Doug explained that all the students were being protected from both health risks and from any potential discrimination. Doug was careful to never mention Henry's name. He left that for Joan and me. Together we told the Board our story and Henry's issues. There was just stunned silence. There was no other immediate reaction. Joan and I

began to believe that that we really had kept our secret. People did not know.

Superintendent Bradshaw reminded the board of the need to keep the secret until Henry himself told the story to the public. It was his story and his alone to share when he was ready. Dr. Bradshaw cautioned that there was a legal requirement by the State of New York for the school to not disclose this confidential information. As school board members they too were bound to keep the secret. From the hugs we got as we left the room, Joan and I knew we had the support of the entire school board not just in keeping the secret but in supporting our family. Nearly every adult who learned of our family plight seemed obliged to shake hands or offer and receive hugs. It seemed as though they needed to give us a physical affirmation of their support.

The next day on Thursday afternoon, Joan and I met with the school faculty. Most of the teachers present in the room knew Henry. Many had him in class. They almost all knew about his Hemophilia. None of them even suspected that Henry might have AIDS. Joan and I cried as we told them about our son, his transfusions, and his contracting the virus. Henry's hematologist, Richard Horner, M.D. and an infection control nurse, Ann Vamvakias, R.N. explained the medical complications for Henry and the implications for the public.

"Henry is no risk to anyone doing what people should do in a public school setting." Dr. Horner stated dryly and matter-of-factly. "Henry is at far greater risk from us because of his weakened immune system than we are at risk from him." he concluded.

There were no questions. The faculty was silent. They were stunned. They had seen Henry in school almost every day for months. They watched him in gym class and in social studies and in the lunch room. People couldn't tell from looking at him that there was anything wrong. He seemed perfectly normal, except for having a fatal illness!

Joan and I didn't know what else to say. The faculty didn't know what to ask, and the doctor and the nurse were finished.

As the time for questions passed in what seemed like an impossibly long few minutes, Dave Fundis, one of Henry's teachers got up. He made a brief, eloquent and emotional speech. He spoke of how it was so unfair for this epidemic to have visited our school, our community and our family. Dave was lost in the emotion and was unable to conclude his speech. He sat down in tears. There was not a dry eye in the room. Henry had the support of the faculty.

Friday morning, the day of the press conference, dawned early in the Nicols household. Jennifer had come home from college to be with us. We convinced Diana that she should stay in school and that we did not need more support in Cooperstown. This was a decision we have oft regretted. If we had it to do over again, we should have asked her to be present for the news conference too. She probably needed to be with us. We needed to have her with us. We should have been together.

Henry had arranged to meet with some of his best and closest friends that morning to tell them that he had AIDS. He did that privately one to one.

The rest of the plan still focused on the school. Uncertain how the students might react, the decision was made that Joan and I would reveal the story to Henry's peers and student colleagues. My father, Henry's grandfather would stay with Henry to keep him company. The plan was that entire student body of the Cooperstown High School would become insiders. We already had the support of the board and the faculty. We were now asking for support from the students.

As Dick Horner, Ann Vamvakias, Joan, and I repeated our story about Henry's Hemophilia, blood transfusions, and AIDS, the students sat in awkward but respectful silence. This was serious business. The kids knew it. Like the adults from the night before, they were unsure how to act. I watched as Dr. Horner and Ann Vamvakias spoke in medical jargon to

uncomprehending ears. The children looked around the room at each other and at their teachers. The teachers were not frightened.
They were sad and perhaps melancholy but they were supportive of our family and of Henry. They were truly concerned for us and for our plight. The kids had some questions. How long would Henry live? Should they do anything to protect him from them? Where was he now? As they finished their questions, I knew that now we won over the board, the faculty, and the students. The students had modeled the behavior of the teachers.

The school sent out a letter to all the parents in the district. The letter was intended to arrive in people's mail boxes on Friday the day of the announcement. When the children returned home, they could explain what had happened at school to their parents and together parents and children could watch the news on TV on Friday evening or read it on Saturday morning. As they were the first informed, they would know what was to come. They, the members of our community, would all be trusted insiders.

Friday morning at 11 A.M., we all gathered in the meeting room of the Boy Scout service center. The room was packed with reporters from every newspaper and radio and TV station within a 75 mile radius. The news media had been lured by the promise of a Boy Scout with AIDS going public about his disease. This was going to be big news.

Troop Committee Chairman, Bruce Reinholdt called the press conference to order. Joan, Jennifer, and I sat off to the side at a small rectangular table. Joan and Jennifer were already crying, frequently dabbing their eyes with tissues from a nearby extra large box. I had a wad of tissues in my hand to absorb not only tears but the sweat from my clenched fist. The tension was incredible.

We were winning our battle of making a secret public and we were getting public support, but so far we had only tested a

friendly and more intimate crowd. This was the public. So much depended on what would happen in the next few minutes.

With the help of the committee, Henry and the senior Scouts had arranged the room so there was an American flag on the side of the speaker's podium. Behind the speaker was the easily recognizable *fleur de leis* emblem of the Boy Scouts. In front of the podium were seven chairs facing the audience, one for each of the six members of the Senior Patrol and one extra chair.

The boys filed in following Bruce's call to order, all eyes and cameras were on the extra chair. Bruce then said that he wanted to introduce Senior Patrol Leader Henry Nicols.

Henry stood up from his chair and took the podium to begin his message. He said, "My name is Henry Nicols. I am a seventeen year old Life Scout. To earn my Eagle Scout badge I must do a project that demonstrates leadership and is of service to my community. I have decided to do an education project about AIDS. I have AIDS."

It was instantly obvious that there was no way to tell that it was Henry who had AIDS. He did not look sick. He looked like his friends seated in front of him. You can't tell someone has AIDS by looking. His education project was underway.

Henry's courage was overwhelming. Experienced reporters and camera operators, radio interviewers, all stood in contagious silence. Kim Hummel was the reporter assigned to the Cooperstown news bureau by the *Daily Star* a regional newspaper. She was an experienced reporter. Kim had been a journalist for years and, because of my roles with the police department and our very active Scout troop, she had interviewed me many times. Kim was a seasoned reporter who had covered crimes of every ilk and had been present at the aftermath of unspeakable horror caused by both accident and design. I knew her well. I had discussed homicides and fatal accidents with her and knew her professional demeanor. When I looked across the room at the assembled media at Henry's press conference, I saw her cheeks wet with tears. This was

different from anything she or any of the reporters present had ever covered. This was not just a tragedy. It was not a just a horrible accident. This was a tremendous injustice perpetrated by nature on an undeserving young man, his family, and community, indeed on the whole world. But that alone was not the reason for the tears in the room. Henry embodied courage in the face of all those things. His message was hope, where most had none.

Everyone in the room, family, friends, associates, neighbors, Scouts, reporters could imagine themselves in Henry's situation and in the situation of our family. Each measured themselves against this standard. "Would I have the courage to speak the words describing my own mortality, if the message were mine to give? Could I have this courage if I were only seventeen years old?"

Everyone was touched.

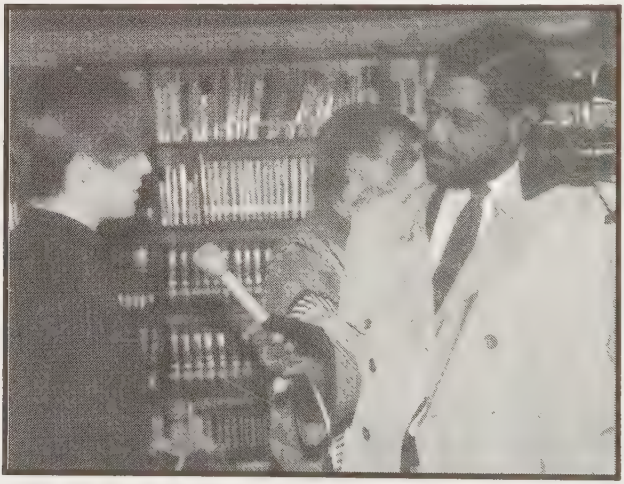
Henry went on to explain how he had contracted AIDS through one of the many blood transfusions he was required to have for his Hemophilia. He went further to explain that he was still physically active but that a recent turn of events had changed his diagnosis from being positive for the AIDS virus to having full blown AIDS. He was now an AIDS patient, and as an AIDS patient, he was unwilling to remain silent about his condition any longer.

"Being infected with AIDS isn't dangerous to people. Being ignorant is. My project is to combat ignorance. I want to teach love, compassion and understanding. AIDS isn't dangerous. Ignorance is."

The reporters had lots of questions. It was mid afternoon when the press conference finished, and we headed out for pizza to feed our hungry Scouts. Henry's plan was working perfectly. Michael, Marianne and Jane our public relations consultants had suggested the late morning news conference. It was their good idea. The reporters would have to leave

shortly thereafter to publish or post their stories. We could all go home to the relative quiet of our home in Cooperstown to wait the televised evening news results of our efforts. We did not want to be in the limelight any more that day. It was a good idea but it just didn't work.

Our plan for the evening included going to a community dinner at the high school. The spaghetti dinner was a fund raiser for a young Cooperstown woman, who had been seriously injured in a recent motor vehicle accident. When we returned to the school, a television news satellite uplink truck was parked outside. I thought it unusual for a TV station to be covering a community spaghetti dinner. Then I realized it wasn't for the dinner. It was for Henry.



11. Henry being interviewed by Ken Screven

Ken Screven is tall. He is professional. He is persistent. He wanted to interview Henry in greater detail. But he had a problem as he traveled around Cooperstown. Ken stood out. He was well known as a news reporter for the CBS television affiliate from Albany. His native New York City accent and his booming baritone voice gave him away. The satellite truck was another give away. When Ken asked for directions to our home, no one would tell him where we lived. Cooperstown was protecting us. They knew that we wanted to protect our privacy even though Henry had made a very public statement. The citizens of our community were modeling the behavior and the support of the children from the school.

Our concentric circles of trust had worked. We had trusted the Board of Education and the faculty of the Cooperstown Central School, then Henry's friends and the students and their families, and then community and now, for the first time, they were protecting us. They wouldn't even tell the news media where we lived.

I spoke with Ken that night at the spaghetti dinner. I explained to him that we would be glad to visit with him again later, but now, tonight we were going to a dinner to support another member of our community who needed help. Henry's story was done for the day. Ken was respectful and compassionate. Over the years that would follow, he became a family friend who interviewed each of us several times. The interviews would continue, but tonight spaghetti waited. Ken joined us for dinner.

Instinct told us that it was going well. The 6:00 pm and the 11:00 pm local news reports were good and supportive, they were obviously only the opening story in what was to become ongoing fodder for the media. The story was developing a life of its own.

Everyone was anxious. We knew from talking with Superintendent Bradshaw that he had made plans in the undesired event of a school wide boycott or demonstration against allowing Henry to remain in school. We were all concerned, of course, knowing that ignorance and controversy would be a better story than harmony. We were determined, however, to be producing as much harmony as we could manage.

The Saturday morning news papers were great. Henry was on the front page of nearly every paper for 75 miles. There were pictures of Joan, Jena, and me wiping our eyes with clenched Kleenex. Henry was stoic and his Scout buddies surrounded him as if to protect him from any harm that could come his way. If only they could.

The phone started to ring early that Saturday morning. There were follow-up interviews with the Associated Press and with each of the reporters and agencies represented at the press conference. Henry was news. Henry's story and the drama that still waited from the community reaction was potential news.

Sunday was a quiet day, we all stayed home and waited for Monday and the start of a new day at school. Henry was no longer a secret AIDS patient. He was now famous in our community. He was Henry, the Boy Scout with AIDS.

Monday arrived, and the Cooperstown Central School bell rang as it did every school day, on time. The day went exactly as scheduled and hoped. Everything was calm!

The weeks and months that followed were a blur. When Diana returned from college, for summer break, she described the transformational change as amazing. "Every phone call, every letter, every question, everything was about Henry." Diana was hardly exaggerating.

Henry spent lots of time hanging out with his friends and Scout buddies. Michael Bedworth and Chris Vancour were his two best friends. They, one or the other, were his constant companions. Henry once referred to Chris, who looked a lot like Henry, as his twin brother. It was good for Henry and comforting to Joan and me to see Henry protected by his friends and still a part of his social network.

We were constantly in the news from front page articles in our local news papers to articles occasionally picked up by Associated Press, to television and radio interviews. Henry was interviewed on NPR, National Public Radio *All Things Considered*, on the ABC news program *Good Morning America* and a number of other TV news channels. Henry began to receive more and more frequent requests for interviews and invitations to speak to groups. During one of the interviews in the living room of our home with an Associated Press reporter, Henry, still surrounded by his Scout buddies was asked if he had ever encountered any negative reaction to his condition.

He said that he had not. Seated next to me was Michael Calhoun, a Boy Scout friend of Henry's. Michael is big. His nickname was "Beef," and with good reason. "Beef" leaned across to speak with me and in a quiet but firm voice he said,

"There were some red necks in the school, but we spoke to them."

I always wondered, but never asked, what it was that Michael could have possibly said to the "red necks". I am not sure that I wanted to know. I am sure that "Beef" had presented a persuasive and convincing argument.

Henry and his story were supportively featured in the popular and gossipy *People Magazine* and in the phenomenally well read Sunday *Parade Magazine* which then claimed a circulation of about 30 million and a readership of more than 70 million. From what happened next we suspected that 70 million people really did read about Henry.

Lynn Minton, the *Parade* columnist who came to interview Henry, was so impressed with his story that when she went back to New York to write her article, she convinced her editors to make it a cover story. That meant that when the story came out in the summer of 1991 Henry's photo would be featured on the cover. We were all very excited. We were more excited when we found out that Eddie Adams was going to take the cover photograph. I had recognized the name. Eddie Adams, Pulitzer Prize winner, was the American photo journalist who was famous for taking pictures of celebrities and politicians. But he was most famous for taking the 1968 photograph of Police Chief General Nguyen Ngoc Loan executing a Vietcong prisoner on the streets of Saigon, Viet Nam during the Tet offensive.

Eddie and a photographic assistant were sent to Cooperstown for two days. Together they snapped hundreds of photographs of Henry in dozens of poses, looking to capture the essence of the character and the soul of a seventeen year old Eagle Scout who had AIDS. Henry had the dreaded death

sentence and scourge of our age that so many were afraid to even speak about. Not only was he willing to speak of his own mortality, he insisted on calling attention to the disease.

Clearly Henry was not ready to "*go gentle into that good night.*"[vi] Eddie Adams who had seen so much death and suffering in Viet Nam, was the person who with his photographs of the Vietnamese boat people, had changed the mind of then American President Jimmy Carter to grant asylum to the boat refugees. It was Eddie Adams who had photographed Mother Theresa holding an armless child at her orphanage in Calcutta. That same Eddie Adams was not satisfied with any of his hundreds or photographs of our son Henry. None of the pictures quite captured the image that Eddie Adams needed.

Later that week after he returned to his home, Eddie called us. Would we mind joining him at his home for a weekend barbeque so he might again try to get ..."Just the right picture....," he asked. Of course we agreed.

"Oh, could you bring your dog?" he asked as if an after thought.

The next weekend Joan, Henry, Nanda (our collie mixed breed dog) and I all drove the two hours to Eddie's home in Jeffersonville, NY near the Delaware River. It was a beautiful spring day. The sun was bright but not hot, and the grass was newly colored bright green. Eddie lived on a large old farm that he had converted into a photo workshop and memorial for the many combat photographers and journalists who he had worked with, some of whom had died taking photos or getting stories in combat zones.

12. Henry photo by Eddie Adams

After a simple barbeque, Eddie and Henry set immediately to work taking pictures. Eddie was

obsessed with the truth. He once said, "Still photographs are the most powerful weapon in the world. People believe them; but photographs do lie, even without manipulation. They are only half-truths."

It seemed as though he needed to capture just the right image and he would know when he had done it. Eddie wanted this image to be the whole truth, a perfect picture. He expected that everyone would be able to know the truth about Henry and his courage from that one image.

When he was finished taking the pictures, Eddie sent us the hundreds of photos that he had rejected. He revealed to us which one he had selected for the cover. We were pleased.

Eddie wanted to get a photo of Henry that would capture his strength and courage and yet still show his innocence, as though innocence in the age of AIDS was important. Eddie believed that Henry's Scout uniform spoke volumes about the reason for his courage and his project. The dog spoke of trust and loyalty. Henry's look implored compassion and showed innocence. We agreed that Eddie had selected exactly the perfect picture.

In June of 1991 Henry graduated from high school. In July, he received his Eagle Scout Award. Both ceremonies were attended by hundreds of well wishers. At the Eagle Scout ceremony, Henry announced that he had enrolled in the pre law program at the State University of New York at Albany but would be taking a year off to travel and to speak. He would continue his Eagle Scout project— his message of compassion and love for everyone and especially those with AIDS. There were tears and hugs. All knew that Henry was not likely to graduate from any college. He was not likely to finish even a year as a freshman. It was not likely that he would live that long. Again, people were impressed by his courage.

Then the cover story in *Parade* magazine hit the news stands. We thought that our lives had become public before

that. We were wrong, very wrong. We had now become very public. Diana's observation that every call, every letter, every question was about Henry became even more prophetic and correct. In the days and weeks that followed, we answered hundreds of phone calls. We received thousands of letters. More than one letter was simply addressed: *"Henry Nicols, Eagle Scout, Cooperstown, NY."*

13. Parade Magazine Cover Photograph

Cooperstown had long been described as the quintessential American town. It was the birthplace of baseball and the home of the National Baseball Hall of Fame. In 1991 it also was known as the home of "Henry Nicols," the Boy Scout with AIDS.

Cards and Letters, Hope and Cures

As a family we were constantly surprised and amazed at the outpouring of support we continued to receive. By the end of the summer of 1991, we had received nearly ten thousand cards and letters, many more arriving daily. Henry received so many cards and letters that we had a group of close friends and family who volunteered to help sort and classify them. We responded to very few, but as many as possible.

There were letters from spiritual people who were praying for Henry and for our family. They had all sorts of proposed prayer solutions and hoped for miracle interventions requested from a generous and compassionate God on Henry's behalf.

There were letters from religious nuts. These people sent suggested miracle cures that would or could be instigated by obscure rituals or incantations. Some of these were from people who belonged to recognized churches, most were not.

There were hundreds of letters from people who believed that they had cures for AIDS including; diets, home remedies, life style changes and watching certain television programs.

There were hundreds of letters from young girls. The notes from girls almost always were from girls aged 14 to 24. They almost always began in the same way.

"I have never written a letter like this before..."

Then they would go on to original prose. Many of the girls offered to continue corresponding with Henry and gave their return addresses and phone numbers. Most of the letters in this category included a photograph. Some of the letters included proposals of marriage, a few just wanted to bear his children. Henry and his friends Chris and Michael spent hours reading those letters.

Henry or his sisters responded to some of the letters that struck a personal chord or resonated with one of us for some special reason. We were getting sympathetic mail from people who, like we had, were still living a secret life, afraid of revealing their AIDS or HIV status. Many of the most touching stories came from family members of AIDS patients who sought to console or receive consolation because they, like us, had been involuntarily touched by AIDS.

There was also a section of letters that we sorted in the *"Nutburger"* category. These people thought that Henry got AIDS for some sin committed by him or a family member or society in general. These people thought that AIDS was punishment from God. In this collection were people who thought that people with AIDS should be quarantined to protect society. The idea of quarantining AIDS patients had been already debunked by the U.S. Surgeon General but it was still supported by some people who like then Senate Candidate Michael Huckabee, the future governor of Arkansas and a future Republican presidential contender thought that "carriers of this plague should be isolated from the general population". Huckabee and scores of other people should have known better. They didn't!

There was even one letter written by someone clearly conflicted, who thought that people with AIDS should all be locked up but since Henry was an "innocent victim" he should be allowed to watch television.

We didn't show Henry those letters!

Most of the thousands of letters were from people who just wanted to offer words of support to Henry and to our family. We started to answer the letters, but we were quickly overwhelmed by the sheer numbers of the response. Even now nearly two decades later we still think about the overwhelming support that Henry received for his project, and how that article in *Parade Magazine* changed all our lives.

In the summer of 1991 Henry turned 18 years old and he was invited to go to the National Institute of Health (NIH) in Bethesda, Maryland to participate in an experimental round of

treatments. Henry's immune system had deteriorated to the point where Henry had little to lose from an experimental treatment. The NIH, under the guidance of Dr. Anthony Faucci had begun several experimental protocols looking for one or more drug treatments that would slow the progress of the disease and perhaps restore Henry's weakened immune system. The NIH flew Henry and me down from Cooperstown for the first treatment. Henry was admitted to the hospital. Although he was not visibly sick at the time, the effect of the drug was still unknown. The NIH placed me in a nearby motel. The evening of the treatment I was asked to leave the hospital room so the initial dose of the experimental drug could be administered. The potential side effects were unknown and the doctors and nurses did not want to have an anxious parent in the room just in case there was a crisis. I waited anxiously outside as the dose was administered. Henry, as usual used his humor to defray the stress of the moment. Even in this moment he would joke with his doctors and nurses. He was amazing. I am sure he knew the potential risks. With this experiment he volunteered to be a human lab animal in the hope of helping to find a treatment for this still incurable and untreatable disease. It was because of hundreds or even thousands of people like Henry who had nothing to lose, and who all hoped to gain just a little hope that the first round of antiretroviral drugs were developed. Henry had several more flights to Bethesda, accompanied by either Joan or me. In the end, his experimental drug like so many others that were tested made no difference to him or to anyone else.

But because of experimental tests like this one AZT or Zidovudine, the first of the proven AIDS treatment drugs became an option. As quickly as AZT was approved for use, Henry was put on it. The drug side effects of nausea, headache, anemia and bone marrow suppression were a big but necessary price to pay to try to delay the progression of a relentless virus that was slowly but steadily claiming Henry's immune system. AZT and all of the other AIDS treatment drugs do not cure AIDS. They just slow the seemingly inevitable

progression of the virus and the accompanying failure of the immune system.

Over time, as Henry's fame continued to grow, he had many more miracle cures offered to him. One person was a sad but sincere man who contacted us first by letter and later by phone. He had lost his son to AIDS earlier in the epidemic. After his son's death he had worked on and developed a homemade inject able remedy that he had tested on hamsters. He did not have a laboratory, and he had never tested his cure on the AIDS virus but he was sure it would work. As proof of its lack of toxicity he even tested it on himself. He had survived without harm although he claimed his miracle drug had made him sweat a lot. He was convinced it would work to cure AIDS, although it had never been used on an AIDS patient. He sincerely wanted to help and was obviously distraught at the loss of his own son, who he had been unable to help. Our hearts went out to him and we spoke to him often but declined to use his "sure cure".

Another man from Dallas, Texas, claimed to have set up a complicated chemical experiment to have a cure for AIDS. He was afraid that the government would kill him if they found out that he had the cure. Like others then and now, he believed that AIDS was the product of an American Government Central Intelligence Agency experiment in chemical or biological warfare gone wrong. He called us weekly to check on Henry and his progress and he always declined to give his name or phone number. He was afraid that he could be tracked by government agents so he called us from pay phones, different ones each week to avoid having his phone calls being traced. He called himself Al Chemist and was sincerely worried about our son. After about six weeks of regular phone calls we agreed that if or when we were desperate enough to need his help, Joan or I would put a notice in the personal ad section of the *Dallas Morning News.* We were instructed to have the ad simply read. *"Al Chemist - Call Hank."* He would then contact us. Although we became desperate, very desperate, we never placed the advertisement. I have often wondered who he was, and how he fares.

Other people sent us cures including holy water from Lourdes in France and video tapes of fundamental Christian healers healing all manners of illness. We received religious artifacts and blessed objects from many alternative faiths and traditions. We tried to acknowledge as many offers as we could and while we accepted prayers and good wishes, we always declined those very kind and sincere attempts at cures.

Joan and I hoped and prayed for a miracle, but we looked to science to provide it. We believed, but also believed that faith would not be enough. From our experience, it was obvious that we were not the only ones touched by AIDS, or by Henry's story of AIDS. Henry and our family had touched the lives of many and in turn many people's stories touched us.

Henry's story was very compelling, hope in the face of hopelessness always is.

The Speaking Tour

After his announcement, Henry spent much of the spring and summer speaking to local school groups, service clubs, and other organizations. We traveled locally within about a hundred mile radius speaking to anyone who invited us. One of the people who had read of Henry was a man who lived about a two-hour drive away. He read of the Eagle Scout project and asked if he could meet with Henry and watch one of the presentations. It was in May of 1991 before the *Parade* article that Michael Ryan met us at a local school presentation and sat in the audience.

By then Henry and Jennifer, who had left her college studies to travel with and support her brother, had developed a standard template for high school presentations. Michael Ryan attended one of those presentations.

I as the designated driver on those trips would collect Henry, Jennifer, and 3-4 volunteer Scouts from our troop. Together we would travel to the school or location where we would provide a 45 minute long assembly program. The program was usually requested by a school administrator, a health officer, or a nurse who knew someone who had seen Henry present or had heard about his Eagle Scout project in the papers or on TV.

Although there were variations, the program would begin with Henry and three other Scouts in uniform sitting on the school stage. After being introduced by the school host, Jennifer would begin the program.

"Hello, my name is Jennifer Nicols and my brother Henry is going to talk to you in just a few minutes about AIDS. But before I bring him out, I just want to tell you a little about Henry. He has been sick, but he doesn't like it when people treat him like his is sick. So please try not to make him

uncomfortable." Gesturing off stage, she continued, "Here is Henry!"

The school host would then enter pushing a wheel chair with a frail looking scout wrapped in a shawl. The host would then help the fragile "imposter" stand to approach the microphone. Once there, the "imposter" would say, "My name is Chris Glockler. And I don't have AIDS. Now let me introduce the real Henry Nicols." Chris although not sick was thin and did a great impression of someone who was on death's door!

Henry, who had been seated on stage the whole time, would rise and start to speak. "Ok," he began. "My name **is** Henry Nicols and I **do** have AIDS. But before I begin my presentation, let me ask you a question."

Henry would pause for dramatic effect. "How many of you thought that Chris was me?" Then, he would wait as hands crept slowly into the air. "Come on. How many of you thought that someone with AIDS would be a sickly kid in a wheelchair?" By now most hands were in the air. Henry went on from there. "That is the first and most important lesson. You can't tell that someone has AIDS by looking."

Then, Henry continued his story. He would explain about Hemophilia and how he contracted AIDS from one of the many blood transfusions he had received while growing up. He would explain what it was like to have HIV and not know if you were going to get AIDS. Finally, he would tell what it was like to have AIDS and what it was like to not be able to tell anyone that you had an illness.

Henry would often end his presentation by saying, "AIDS isn't my disease. It is our disease. It is going to affect all of you unless we recognize that it is only a virus. It is not a punishment from God."

To conclude the presentation, Jennifer would rejoin Henry on the stage and take the microphone from him. She would reiterate, "In our lifetime, AIDS is going to affect everyone in this room. Each of you here today will lose someone you know

and love to AIDS. The difference between you and me is that I already know who it will be!"

After a few seconds to allow time for her comments to sink in, Jennifer would then ask for questions. We seeded the audience with at least two people with questions to "break the ice". We believed that people wanted to ask questions but often did not want to be the first to do so.

Some of the more common but unseeded questions included:

Question: What is it like to know you are going to die?

Henry: "I don't know that I can answer that. What do you think it is like to die? We are all going to die. What do you think it is like? We just don't know when we are going to die. If I stop living my life now and wait to die, I won't be living. So my plan is to live my life the best way I know how. I am not going to die today."

Question: What is it like to be an "innocent" victim of AIDS?

Henry: "I hate that question. If I answer it, there is an implication that there are guilty victims. And I know this, there is nothing anyone could do to deserve having AIDS. Even if you could say a person 'sinned' by being a drug addict or homosexual, I don't believe God would punish them and their families. Because there is no such thing as a guilty victim, I don't know what it feels like to be an innocent victim."

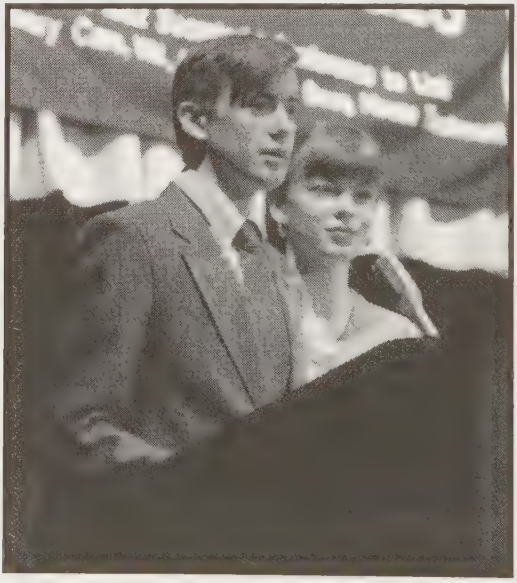
Question: Does it hurt to have AIDS?

Henry: "Yes, some days it does. Sometimes I feel like I have the flu and am too tired to even get out of bed. Some days, when I am really sick, I need to be in the hospital. That surely doesn't feel good either. But most of the time, it does not hurt to have AIDS."

And the questions would continue until our allotted time had run its course, and we had to end. After the presentation, Henry was mobbed by the audience, straining to shake his hand or give him a hug. It is a powerful thing to be in the presence of someone who can speak of their own mortality and so bravely face death.

It is a powerful thing to shake the hand or hug a person with AIDS. It is as though the mere touch of a person with AIDS denies death victory over the day. Henry was often the first person with AIDS that many people would ever meet. As Jennifer had concluded in her remarks, he would not be the last AIDS patient the members of the audience were likely to meet.

Michael Ryan was impressed with the presentation and Henry. Michael was an author, but he was also an independent video producer. We did not yet know it, but Michael was planning to write and produce a documentary about Henry.



14. Henry & Jena on tour

Michael interviewed Henry that day and a few days later Michael called back with a proposal. He and a group of his partners wanted to produce a documentary about us and our struggle with AIDS! We immediately liked Michael and his partners, Deborah Gilbert (Michael's wife) and Ellen Stokes. The entire family was caught up in the idea of the documentary and of helping Henry to tell his story as we best could. And over the course of the next several years Mike, Deborah, and Ellen along with their sound technician and camera person followed Henry and Jennifer on their speaking tour.

Activism, Awards and Antics

By the fall, Henry and Jennifer were receiving so many requests to speak at high schools and colleges that we needed someone to manage their contacts and calendars. We hired Lordly and Dame, a Boston based agency that specializes in managing educational speakers. Over the next two years Henry and Jennifer were on the road almost full time. They returned home in between speaking gigs to change clothes, pick up mail and visit with the family. Henry and Jennifer were at the top of their game. Henry was even invited to speak at the Federal Bureau of Investigation's training facility in Quantico, Virginia on World AIDS day, Monday December 1, 1991.

15. Henry and Jena at the FBI

As a chronically ill child, Henry learned early on how to manipulate any situation to get what he wanted. He had lots of practice with his doctors, nurses, parents and siblings. He was in rare form when he and Jennifer were picked up at the Washington National Airport to be driven to the FBI headquarters in Quantico, Virginia. The Director of the FBI had sent his personal limousine and driver who was also an FBI agent. To ride in an armored limo loaded with police emergency equipment including lights and siren was a treat for Jennifer and Henry. After leaving the airport the limo was immediately caught in the typically tedious traffic of the metropolitan

Washington, D.C. area. Henry seated in the front seat with the FBI agent driver suggested that they could use the siren to clear traffic and make better time on the long drive to Quantico. The agent politely explained that the lights and siren were to be used for emergencies only.

Refusing to take no for an answer Henry pushed on, "Come on. You know you want to."

Moments later the crowded Washington, D.C. traffic yielded to yet another black limousine. The lights and siren wailed as the limo wound its way through the traffic to some unknown but highly important appointment. Henry was right, the agent wanted to.

The presentation was scheduled to take place in the Bonaparte Auditorium with the Red Room available for overflow seating. The men and women of the FBI crowded both rooms to listen to a courageous young man speak about compassion and the need for understanding. They heard the message that AIDS is not dangerous. Ignorance is. Henry loved presenting to audiences especially those who loved him. This venue was no exception as the audience and Henry connected.

16. Henry @ FBI Academy shooting range

Often Jennifer and Henry asked friends to accompany them on the tour to help with the details of day. On this occasion Henry and Jennifer were accompanied by Todd Curtis, Jennifer's boyfriend and Dana Swift, a family friend. They acted as "roadies" for this gig and relieved Jennifer from many of the routine chores. This way both Henry and Jennifer could focus on the presentation.

Todd and Dana enjoyed their affiliation with the FBI as well. They got to shoot automatic weapons as well.

After his presentation to the Academy, Henry and the group were invited to the shooting range where they were treated as V.I.P.s and allowed to play with a full range of weapons in the indoor firing range. Henry was having the time of his life. He was speaking about important issues. He was meeting people he admired and respected, but best of all, he got to play as well.

After leaving the FBI speaking engagement, Henry and Jennifer moved on to meet with President George H.W. Bush in the Oval Office. Henry and Jena made a brief presentation to the President about the need for AIDS drugs to be covered by insurance companies. They also argued that uninsured people with AIDS needed to receive government assistance. President Bush, brushing them off, asked his aid to get the names and addresses of Henry's parents, and he would see what he could do to help. Jena told the President that it was not our family that needed assistance. We had insurance, but millions of Americans with no health insurance did need help, including thousands with AIDS. The President again offered Henry help. Then, in just minutes, they were politely ushered out of the White House.

Jennifer later said that the most impressive thing about the President was his stature. She said that he was exceptionally tall and that perhaps the best thing about the meeting was that Henry and Jennifer played with "Ranger" the son of "Millie" the famous Presidential dog who coauthored a book with first lady Barbara Bush. The encounter was frustrating, there was no substance.

"Dad, the President just doesn't get it!" Henry told me that night when reporting on the meeting. He was right, the President didn't get it. We never heard from the President or his aid in spite of having our address. The President was not the only celebrity with whom Henry met. New York State

Governor, Mario Cuomo did seem to get "it". Mario was someone whom we had hoped would have more national responsibility, but unfortunately, he was then at about the end of his political and public career. But he did invite us to the New York State Capitol to meet his special guest, movie star Arnold Schwarzenegger who had just finished filming the movie *"The Terminator".*

At the request of President Bush, Schwarzenegger was on a speaking tour to promote physical fitness. Arnold posed with Henry and helped to adjust his hair for a better camera view. At the end of Henry's celebrity studded day visiting the Governor and a Super Star, Governor Cuomo gave Henry a leather jacket that had been given to Cuomo by Schwarzenegger, who had been given the jacket by President Bush. (Talk about re-gifting!)

But not all of 1991 was fun and celebrities. Henry was starting to get ill. As the year progressed, he developed a fever and was quickly diagnosed with pneumonia. This pneumonia was not a typical pneumonia that normal people get, but pneumocisitis pneumonia, a rare pneumonia found almost exclusively in AIDS patients. His immune system was weakening.

At about that time a young woman from Fort Pierce, Florida named Kimberly Bergalis claimed to have contracted AIDS from her HIV positive, homosexual dentist, David Acer. Acer, who had died the preceding year of AIDS, was linked by the Center for Disease Control using sophisticated DNA testing to a high probability that he had infected Bergalis, perhaps purposefully, perhaps criminally. Kimberly was a sympathetic figure and she was dying of AIDS.

Carried in to a Congressional hearing on her deathbed, Kimberly Bergalis testified before a frightened public and the United States Congress that health care professionals should be required to be tested for AIDS. Her suggestion was that every doctor, nurse, and healthcare provider be mandated to take a test to determine if they had been exposed to HIV. Kimberly's ill-thought out plan was encouraged and sponsored

by conservatives and others who were lobbying for the required mandatory testing of health care professionals. These same conservatives believed that it was the evil homosexual and drug abusing population who were spreading the disease. They blamed the continuing rapid spread of AIDS on the very people who were being most responsive to the epidemic- AIDS activists and homosexuals. The Bergalis Bill would have cost a fortune and further diminished already scarce financial resources.

Immediately after Kimberly Bergalis testified, Henry and Jennifer both followed with their own testimony before the same Congressional panel. Jennifer and Henry both spoke about the tragedy of "innocent" victims like Kimberly and Henry. Together they reminded the panel that any monies spent on mandatory testing of health care workers would be a waste of money and the bill would further stigmatize people, frighten the public, and not do anything to lower the rate of HIV infection. "Universal precautions" the treating all blood and body fluids as potentially infectious was what was needed to be done. Kimberly's case was sad and tragic, as was Henry's but it did not justify bad law. Jennifer and Henry testified that the Bergalis Bill would have isolated HIV positive health care workers and other AIDS patients. It might even force some people to avoid HIV testing for fear of isolation and discrimination by uninformed or frightened people and healthcare administrators.

Shortly after her testimony, Kimberley Bergalis died in December of 1991. It was an irrational and an emotional time that pitted one "innocent" victim against another. Fueled by fear, the United States Congress nearly passed the Bergalis Bill. Henry and Jennifer are at least partially responsible for logic and science ruling the day.

Later in that same busy month, December of 1991, Henry was recognized by the Caring Institute in Washington, D.C. as one of the ten most caring young people in the nation. Henry was selected by the Institute in part because he refused to be

recognized as an "innocent victim". Henry taught that AIDS did not discriminate in selecting its victims. HIV was a non judgmental virus that would infect anyone exposed. Henry believed that victims should not be segregated by race, gender, or sexual preference. It was a powerful message for a white, middle class Boy Scout to stand with and to defend homosexuals, Haitians, and drug addicts, which was how many Americans still viewed AIDS patients.

The evening of the awards ceremony Henry was not feeling well and was too sick to stay for the conclusion of the ceremony. Jennifer, Diana, Joan and I took Henry up to his room as hundreds of well wishers celebrated his efforts to teach compassion in the auditorium below.

Almost all of 1992 was busy. In recognition of his efforts to defeat the *Bergalis Bill* and to educate the public about AIDS, Henry was awarded the first ever *"Ryan White'* award by the National Hemophiliac Foundation at the annual meeting in Tampa, Florida. Henry was becoming widely recognized in the Hemophilia and AIDS communities as a spokesman and a leader.

Lordly and Dame, our agents found many schools and universities eager to hear the story. Henry and Jennifer became regular jetsetters, traveling to forty-one of the fifty states and speaking to hundreds of college and high school students at a time. Thousands of people heard Henry's message and his story.

Diana, concerned that she was too far away from home for comfort, transferred from College of the Atlantic in Bar Harbor Maine to the State University of New York at Albany. It was a good idea. We needed to have her closer, too.

These days found Henry often sick. He always seemed to have some low grade fever and at least a mild dry cough. He had not fully recovered from his first bout with pneumonia when he contracted pneumonia again. Still, Henry and Jennifer continued their travels. In the spring of 1992, Henry was invited to be the honorary Chairman of the AIDS WALK, San

Diego. The theme of the AIDS walk "You'll Never Walk Alone" seemed especially appropriate. It was an opportunity to work with California AIDS activists who, like people with an interest in AIDS around the rest of the country, were less and less willing to remain silent in the face of discrimination. Henry and Jennifer flew to San Diego to participate in the festivities.

Joan and I were home in Cooperstown when we got the call that Henry had been admitted to a hospital in San Diego. Jennifer was in tears. Henry had a high fever, persistent headaches, neck pain, nausea, sensitivity to light and vomiting. She explained the doctors put him on some major antibiotics as they tried to determine what was wrong. It was too early for any definitive test results but the best guess at this point was that Henry had meningitis.

"If that is true," Jennifer paused on the phone, "he might not be coming home. You need to be in San Diego! The good news, if there is good news in something like this", Jennifer continued, "is that Dr. Davignon is here."

George Davignon was a pediatric hematologist when we knew him at Bassett Healthcare. He was the doctor who had asked us if we wanted to get Henry tested for HIV. It was just a few years before that he had cared for Henry as a child. Joan and I both felt much better knowing that our son was in the hands of a physician we knew. We also knew that George was compassionate and would care for Henry as best he could. That was indeed a good thing.

Joan and I immediately picked up Diana, and together with Joan's mother Rosemary we drove to the Albany airport. We were on the very next flight at six in the morning to California. Not sure of where Jennifer and Henry would be, we made arrangements the night before to meet Jennifer at the hotel where Henry and Jennifer had rooms reserved by the AIDS Walk organization.

It was about 10 A.M. local time when we took a cab from the airport to the hotel. When we arrived, as we were instructed the evening before, we went to registration and asked for Henry and Jennifer Nicols room number.

The desk clerk spoke with us but waived his hand towards the back of the lobby as if gesturing for the bellman. It was then that two big plain clothes no nonsense Deputy Sheriffs greeted us by showing their badges. They, then, asked us for our identification.

"*What is going on?*" I said feeling more than a little intimidated and out of my element.

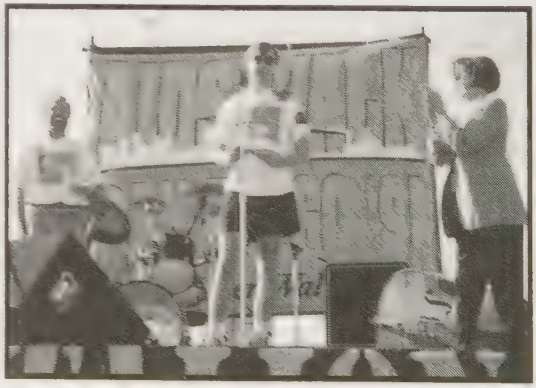
"Nothing," they assured us. "It is just that there had been some threats against the AIDS walk and because Henry is the most visible symbol of the march, he has been assigned police protection."

It was then that Jennifer turned the corner. While the police were identifying us, the registration clerk had called her, and she immediately came to the lobby.

"*Mom, Dad!*" Jennifer was clearly relieved to see us, but not looking as distraught as she had sounded the night before. Jennifer went on to explain that Henry did not have meningitis. He had a staph infection. Once he was started on the antibiotics, his fever broke. Long story short, he had already been discharged from the hospital.

"Well where is he now?" we asked.

"Oh, he is out getting his hair cut at some 'barber to the stars', and then he is going to go water skiing," Jennifer said, as though that were normal behavior for someone who had been described as having



17. Henry @ San Diego AIDS walk

been on death's door the day before! Jen then changed the subject.

"As long as we are all here, tomorrow, we can all do the AIDS WALK." Joan and I should have been used to it. We had raised our son not to think of himself as sick, even if he did have AIDS!

Henry and Jennifer continued their advocacy. They returned to Washington D.C. for another meeting with the President. This time it was William Jefferson Clinton. The Washington power structure had changed. The Democrats were now in control of the White House. The mood was different and there was talk of universal healthcare. We were excited. Tens of millions of Americans did not have insurance and healthcare was either unaffordable or denied to the poor, including those with AIDS. As AIDS activists Henry and Jennifer both believed in the need for universal healthcare coverage and the Clinton administration seemed to be a sympathetic and supportive ally. First Lady Hillary Clinton took the lead on an impressive but ineffective effort to convince the Congress and the country that there was a better way to care for America's sick, but it was not to be, at least not yet!

Our family had often discussed how our health care system was not only biased in who it served but its policies actually were fiscally irresponsible. The cost of not providing health care is higher than the cost would be to provide universal coverage. It is not cost effective or moral to deny healthcare to people. The loss of productivity and the added cost of poor alternative solutions like Emergency visits instead of clinic visits make no sense! We all agreed that if Thomas Jefferson were writing the Declaration of Independence in the 20th Century he would have included "the right to life, liberty, the pursuit of happiness and *healthcare*". But the time was not right, and it was not to be. Universal healthcare was denied in a resounding and embarrassing defeat. We all hoped that universal healthcare will again become a priority but also believed it would not be for decades to come.

When Henry and Jennifer returned from Washington, Jennifer summed up the meeting with the President. "Dad, Bill Clinton is really tall!" she said.

We thought some things changed in Washington, D.C. and some didn't. Support for people with HIV/AIDS and others with chronic illness is still slow to come.

The International Scene

The early days of AIDS epidemic in the United States witnessed fear, prejudice, and panic responses. As AIDS spread world wide so did the fear and injustices. Our advocacy efforts in the states drew a great deal of attention and we were asked to provide support internationally as well. In 1992 we were invited to speak in Japan and the following year we expanded our advocacy efforts to Ireland.

In the late 1980's the global pharmaceutical manufacturers discovered that the American Hemophilic blood treatment products like Factorate ™ were potentially contaminated by the untested blood of donors who might have been exposed to HIV. The pharmaceutical manufacturers did what any profit-making, self-centered, irresponsible manufacturer would be expected to do. They immediately withdrew the product from the U.S. market. This way they avoided the potential liability of selling possibly contaminated blood products. Then rather than destroying these products, they sold them on the global market.

Because the international market in general and Japanese market in particular were less regulated than the American market, it was possible to sell expired or outdated, and possibly contaminated blood products internationally. Thousands of Japanese Hemophiliacs contracted AIDS from American blood products. By the 1990's hundreds had already died, but the Japanese culture which discouraged talking about illness absolutely forbade talking about AIDS.

In Japan, illness was sometimes taken as a sign of weakness and a cause of shame. Because of this .Japanese health care is different from American health care. In Japan, it was not unusual for patients to be treated for an illness like cancer and to never ask their physician what was wrong. That could be a problem, especially for someone with AIDS which was on the rise especially with the spread of contaminated American blood products.

Aids activists in Japan knew that these issues needed to be brought to the forefront. Understanding that keeping the problem hidden would only worsen the consequence and to address this growing emergency, a Japanese AIDS support group invited us to help. Jennifer, Diana, Henry and I accepted the invitation. We agreed to speak about the issues that confronted AIDS patients around the world and in Japan in particular

In January and February of 1993, the four of us traveled together to Tokyo, Osaka and Kyoto, and at each stop we were met by local Hemophiliacs and AIDS patients, and mobbed by television and print media personalities. The four of us all appeared on Japanese national media, and overnight Henry was a celebrity in Japan.

18. Mobbed in Japan

A group of reporters were interviewing Henry about what he wanted to do while in Japan and his reply surprised everyone including Jennifer, Diana and me. Henry without hesitating said that he wished he could visit the Temple of the Ronin.[1] The Japanese reporters were amazed that this young man from New York knew about the Ronin. Henry explained that he knew from his readings of Bushido or the law of the Samurai. Henry explained to us, but did not have to tell the Japanese that Ronin were samurai warriors from the Japanese feudal period who did not have a master. The word Ronin actually means a drifting person.

[1] The Temple of the 47 Ronin is a physical monument to one of the most celebrated stories of the Japanese Samurai. It is a legend of a group of Samurai who gave up everything to live their lives according to their highest law, the law of. Bushido.

Henry told the reporters that sometimes he felt like a Ronin. He felt that he lived his life by a strict code similar to the Japanese law of the Samurai or Bushido, but that he had no one master. He was a Ronin. While at the temple he further impressed our hosts with his knowledge of Buddhist prayer and lit incense and prayed as though he had been raised in the Japanese culture. For the first time I understood why the Japanese samurai sword from Germany was so important to Henry. He was a Ronin.

The Japanese who were already impressed by Henry were surprised that he could talk about having Hemophilia and flabbergasted that he could talk about having AIDS. In a front page article a Tokyo newspaper pronounced Henry a true "Hiro." The word is pronounced the same way in English but it is spelled hero.

Henry's congenial personality and sincere interest in Japanese culture made us celebrities. We were taken to fine restaurants every evening by different hosts. Each of the four of us enjoys a good sushi meal but to be honest, raw fish every night can get old very fast, especially to those of us with western tastes.

It was then that Diana re-introduced us to a nearly forgotten family secret called the "Aunt Terri Technique". Aunt Terri was wife of Tom O'Donnell, Joan's brother. Tom introduced Terri to the family at a Thanksgiving Dinner at Grandma Herzog's home. Grandma Herzog measured the quality of a person by the size of their appetite. Those unfortunate enough to be on diets would never meet Grandma's standard. We were concerned about Terri who was a petite little thing who could in no way measure up on Grandma's appetite scale. Much to everyone's surprise Terri not only accepted generous portions of each offering but took seconds and even thirds. Wow, could that girl eat! We were all impressed with Terri. Grandma Herzog blessed Tom and Terri's courtship and eventually they married. It wasn't until after the marriage that Terri revealed her appetite secret. She was actually a light eater as we had all

suspected. The secret was a zip lock plastic bag in her purse in her lap. Terri never had to say no to seconds. But she never ate them either.

The Japanese culture also finds it impolite to say "no". We certainly did not wish to offend our hosts as the sushi was passed around the table. To honor our host's insistence that we partake of more raw fish, we carefully applied the "Aunt Terri Technique". I am sure during our three week stay in Japan, we threw out many dollars of sushi, but we never offended our very gracious but insistent hosts, thanks to, Aunt Terri!

Shortly after we left Japan, the Japanese Hemophilic Group that we worked with filed a massive law suit against the pharmaceutical companies that had so callously infected the Japanese Hemophiliacs with HIV. We were proud to have helped inspire parents who might have otherwise been silent. Having AIDS is suffering enough. Suffering AIDS in silence is just wrong.

Japan was not the only country where governmental prejudice negatively impacted families of AIDS patients. Ireland like the U.S. was terrified about AIDS, but understanding and education in Ireland were even further behind the U.S. Joan and I had been invited to represent the family at the Cork Film Festival where the documentary about Henry would be shown.

As time for our trip to Ireland approached, we did some research and contacted some AIDS advocates in Ireland. Colin and Declan became our local contacts. We learned from them about the kinds of impact AIDS was having on local tradition, especially in terms of the burial customs of the day. The Irish have long been known for their traditional "Irish Wake" where the deceased is the most important person at the celebration of their life. Irish wakes today still provide a proper send off. Although less formal than in times past, Irish wakes are occasionally rowdy and sometimes take place in private homes. Alcoholic beverages, "keening" and crying, the traditional laying out of the deceased and the praying of the Rosary are

important cultural and religious cultural traditions. AIDS changed that.

Because of a declaration of the Irish Minister of Health, persons identified as having AIDS were required at the time of death to be sealed in a body bag and placed into a special closed coffin. There could be no display of the body and no public wake. The obvious reason was fear of contagion to the mourners. Science confirms that there is no risk of contracting AIDS from a dead person. AIDS is only transmitted by three methods. You could be born to a person with AIDS. You could have unprotected sex with a person with AIDS. You could have a direct blood or other bodily fluid contact with a person with AIDS. (Universal precautions would again prevent that.)

So, the real risk to the living from dead people with AIDS is 0%. Somehow, the Irish ministry of health had misunderstood or exploited the fear of AIDS into a social and cultural change that deprived families of people who had died of AIDS from their last opportunity to traditionally grieve for their loved ones. The families of people who had died of AIDS were already at increased risk of being stigmatized by the community because of their family member's disease. Now, an administrative edict with no basis in science and the stigma was being further propagated and reinforced by the Ministry of Health, who should have been promoting logic and science.

When Joan and I got to Dublin, we met with a member of the Ministry of Health. We spoke frankly of the trauma of having a loved one with AIDS. He understood our pain as parents. He listened to our argument that, if we were not allowed to conduct a normal wake and funeral for a lost loved one, we would be devastated. Joan, as a trained scientist, communicated to him from the logical and the scientific perspective. He knew we were right. He was apologetic and promised us that he would support the return of tradition and logic. Shortly after our visit to Dublin, the Irish Minister of Health abolished the discriminatory practice of excluding AIDS victims from the Irish wake.

Life events and the status quo

We were all settling into the roll of being AIDS activists in our little community and in the world at large.

Mike, Debbie, and Ellen continued working on their documentary video about our family. From time to time they would visit to tape another interview or get some more photos. To provide the most complete and accurate story of Henry's life possible we decided to hire a friend of Diana's from college to collect video footage of Henry to be used in the documentary. Erik Torbeck did double duty and worked both as a videographer and as a great friend to Henry. Erik came with us on family vacations, Boy Scout trips, and backyard barbeques. Erik collected some of the most amazing and personal film footage that would be later used in the documentary. One of the best pieces was the watermelon ritual. Our home had become a frequent gathering place of both Joan and my extended families. Often, in the summer time when the weather was good, the Mauls, the Sianas the Nicols and the O'Donnell's all would gather on our large lawn or in the woods near by in tents and in campers. We would spend the weekends cooking, swimming in Otsego Lake, and waterskiing behind the family boat. Our family barbeques were legend and at more than one Henry performed a watermelon slicing demonstration using his German replica of a Japanese samurai sword. The pieces flew across our backyard deck but the visual image of watermelon being sliced by a samurai was a great photo opportunity. Henry is the only person I know who ever used a samurai sword to slice a watermelon.

Jennifer seemed to be finding her voice as a spokesperson for the family, and Henry was perfectly content to get on and off airplanes at the direction of his oldest sister. Jennifer was able to make light of Henry's growing issues. She would lovingly tease that Henry could get on a plane and not know where he was, have no idea where he was going, and could not have cared less.

Diana settled into school in a new and more urban environment. Jennifer married her high school sweetheart, Todd. We knew Todd forever. He had been a member of our Boy Scout troop and was an experienced backpacker and mountaineer. If Joan and I had another son, he might have been Todd.

Jennifer still takes great pleasure in telling the more than slightly embellished story of her first day in high school when I, dressed in my police uniform with the appropriate handcuffs, baton and pistol, entered the school cafeteria during lunch time. I was there to identify and arrest a tenth grade student for possession of drugs. As Jennifer describes it, I threw the student up against the wall in full view of everyone in the cafeteria, patted him down for weapons and placed handcuffs on him. Leading my prisoner from school, I stopped on my way out to say, *"Have a nice day, honey!"* to my mortified daughter.

Todd Curtis and his family had moved to Cooperstown during Jennifer's freshman year in high school. Jennifer complained bitterly in those days about being the daughter of the local police chief. More than once she said that she *had* to marry Todd. He was the only local boy who would go out with her because he had not yet arrived in Cooperstown and was not witness to that arrest in the school.

Just to set the record straight, the arrest actually occurred in an administrative area of the school, and I only waved to Jennifer while passing by with my shackled prisoner.

Jennifer and Todd's wedding was a beautiful affair and it was wonderful to have Joan's and my large extended families together with all of our friends to celebrate the marriage. Henry was Todd's best man. We danced, drank champagne and visited long into the night. We acted like everything was normal. Everything was normal, for us!

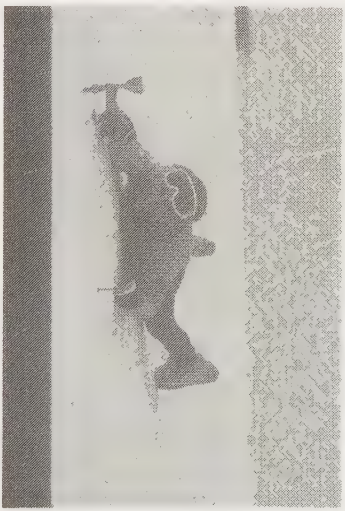
Then, by the end of 1992, Henry was getting sick again. We decided to give both Henry and Jennifer a rest from the travels and AIDS lecture circuit. Jennifer needed some time to spend

with her husband. It looked to us all like the coming years would be quieter than the previous two had been.

19. Howard & Henry @ SCUBA

We took some time off to go SCUBA diving in the Florida Keys and the Bahamas and later led a group of our Cooperstown Boy Scouts on a two week train trip to the Pacific northwest of the United States to climb on Mt. Rainier. We took time to explore the Pacific Coast and the only North American rain forest. Again, we were all focused on the joy of living and spending time together.

Eric, now our personal videographer joined us on our cross country trip to Mt. Rainier where he collected even more video footage of us on the climb. Henry's health continued to be precarious but his sense of humor persisted. When we went to Mt. Rainier, Henry even staged a gag photograph on the Nisqually Glacier near high Camp Muir. He found a patch of snow that had not been walked on and rolled across the snow so as to leave no foot prints. Then, laying on the ground and using two ice axes he pretended to be climbing a vertical ice wall. I took the picture. When the photo is rotated 90' it looks like a bad photo still from a "B" movie, but his antics and the photo still make people smile.



20. Henry on Mt. Rainier

Henry always seemed to be attempting to infuse humor into his own life and the lives of everyone around him. It seemed as though he collected energy from the humor and the good spirits that he inspired in others. It was a good coping mechanism for him and for us.

Henry and Chris Vancour, whom we still referred to as Henry's twin brother, were climbing partners on Mt. Rainier. They had been friends from age nine. According to Henry, they both "thought alike and both had the same sick twisted sense of humor". Chris and Henry got in trouble together, went to school and Scouts together, they hiked across the Grand Canyon, and canoed hundreds of miles on Mountain Rivers and lakes. They took SCUBA lessons and dived as buddies together. Chris was a great source of friendship and support. From the time of Henry's announcement, Chris became his near constant companion. As often as he could Chris would be at our house. The two of them would discuss their real or imagined troubles as they tinkered on cars and played at being seniors in high school.

Chris profoundly offered insight on his feelings towards his almost twin brother in the video documentary:

"I think about it sometimes. I mean if they don't come up with a cure, something might happen to him and he won't be around any more. So, I try to do as much with him as I can. It is kind of hard to explain. You think about your friend being there and doing stuff, and what are you going to do when your best friend is gone? I don't think I could ever have a better friend than Henry."

21. Henry and Chris

Chris was a perfect friend and brother to Henry.

After one of Henry's bouts with pneumonia he was confined to the house while he was recovering. With nothing to do except watch TV Henry was bored. He came up with a plan. He convinced my brother Steven who is a skilled cabinet making carpenter by trade to build a scaffold in our house. The scaffold would have been the envy of Michelangelo painting the ceiling of the Sistine Chapel at the Vatican in Rome. The scaffold held a large platform that provided easy access to a large inside 12' X 12' wall that stretched from the 8' ceiling height above the dining room to the roof level of our clearstory home. The scaffold stretched over the kitchen door. It provided a three foot wide platform that Henry could stand on to access the large white wall that over looked on the dining room.

Henry had been given a medical air compressor by one of our insurance companies. The compressor was used to aerosolize one of the medications that Henry was required to take to treat his pneumocisitis pneumonia. Henry had creatively determined that the compressor could be put to other uses. He disassembled the compressor and with a little tweaking transformed into a small spray gun to spray paint with an airbrush.

From his perch high over our kitchen floor, Henry assisted by Diana painted a large 8' X 10' mural of a mountain scene. There were bright blue skies streaked with high flying clouds and a pristine alpine lake in the foreground and (what else) the Matterhorn in the background.

When the work was finished Steven built a frame of Oak to accent the mural. It looks like a huge landscape picture painted of a favorite nature scene. It is.

Not nearly the scope or quality of the Sistine Chapel the mural has become a part of our family art collection that will live forever. Every time Joan, Jena, Diana or I look at it we are reminded of Henry's creativity and our family adventure to Switzerland.

As Henry's health continued to fail the level and the frequency of our family trips diminished. We tried to plan lots of adventures and always had some short term vacation or family trip scheduled within the near future. His reduced physical capacity and stamina ruled out hiking and S.C.U.B.A and some of the more strenuous plans, and the wheel chair became a near constant companion for Henry and us.

Although he looked mostly healthy, and acted as though nothing serious was going on, those of us who knew him knew that it was a lie. It seemed as though he always had a low grade fever. He was always recovering from pneumonia or some other systemic infection. We all knew, Henry knew too, that AIDS was catching up with him. He did have a fatal illness; it just was not going to kill him today.

What do you want to do before you die?

Henry was asked to participate in a televised national broadcast "Town Hall Meeting" that was to be hosted by Peter Jennings of ABC NEWS. Peter Jennings along with Dan Rather and Tom Brokaw was one of the big three network news anchors. ABC NEWS had decided that a national televised meeting with Henry at center stage might be a good way to further education about AIDS and reduce widespread misinformation and ignorance. We thought it was a great idea. ABC News rented a hotel room for us in downtown Manhattan near the studios from where the program would be broadcast live. Although Henry was sick and not feeling well, he felt it important enough an event to participate.

In the studio the audience was seated in bleachers as though in a high school gymnasium. Peter Jennings with his slight Canadian accent sat in the center surrounded by Henry and a few other guests who were experts about AIDS and the progress of the disease. The format of the program was simple. Jennings would be the moderator and would field questions for Henry and the other members of the panel. The panel would offer information in response to questions from the members of the audience.

Peter Jennings introduced Henry and then began by asking him the first question.

"Henry in your travels to schools and universities teaching people about what it is like to live with AIDS you get asked lots of questions. What is the best question you have ever heard?" Peter asked not having any idea what Henry would say.

"Well," Henry began, "I don't usually get asked this by adults, but children, about 7th grade will sometimes ask. What do you want to do before you die?" Henry replied with almost no emotion.

"And what is it you would like to do before you die?" Peter continued.

"I have thought about it a lot," Henry said, "and I want to run for President of the United States."

Peter Jennings and some others in the audience laughed uncomfortably.

Henry looked right at Peter and said, "Don't laugh! I am serious!"

Peter Jennings immediately and embarrassedly said, "We are not laughing at you, but with you Henry."

"That is part of the problem," Henry said.

"Almost everyone thinks that people with AIDS have the life expectancy of a gold fish and that we don't make long range plans, but they are wrong!" Henry continued. "I am making long range plans and I have it all figured out. In 2008 I will be 34 years old, still too young to run for the Presidency but I will turn 35 during the primary. So my plan 2008 is Henry for President!"

The audience led by Peter Jennings responded with thunderous applause. Henry had stolen the show and the rest of the town hall meeting although informative was anticlimactic. There were a lot of people there that day who would have voted for Henry for President given the chance.

"Eagle Scout, the Story of Henry Nicols" & HBO

Time continued to roll along. Diana, who was always our naturalist child, returned to College of the Atlantic in Maine to finish her degree. She seemed much more suited to a small college in a rural environment, than for one in the big city of Albany. Joan went back to school as well and received her Bachelors Degree from Hartwick College in Oneonta, New York in Medical Technology. She was hired by Bassett Healthcare where she worked in the clinical laboratory in hematology and transfusion services. Jennifer and Todd delivered our first grandchild, Victoria Annalise Curtis who was born on June 14, 1993.

When Diana returned from college, she worked as a rape crisis counselor. This experience fueled her desire to become a police office. She followed her dream and became a member of the police force in Oneonta just 20 miles from our home. Jennifer and Todd had a second child Zachary Julius Curtis. The family continued our daily routines. We went to work. We went to meetings. To any casual observer, life might have seemed very normal. It was normal, just our normal.

The documentary Mike, Debbie and Ellen had been working on was finished. A flurry of activity followed as it and we made the film festival circuit. *"Eagle Scout: The story of Henry Nicols"* [vii] won several awards from different film groups, including the Golden Apple Award for educational films, the Cable Ace award, and Daytime Emmy nominations for its television version. It received the Crystal Heart award from The Heartland Film Festival and The City of Burlington Award from the Vermont Film Festival. It was also shown at the Cork Film Festival in Ireland which, as mentioned earlier Joan and I attended.

The documentary was well received and although it was never intended to be shown on the big screen, its reception and public reaction were so positive that Mike Ryan and the

other producers sought other venues for our story and Henry's message.

It was after the Cork Film Festival, that Michael Ryan, told us about his greater vision for the film.

HBO (Home Box Office) was interested in taking the film that was already done. They wanted Mike and Debbie to add some more footage and then to re release it. We were amazed. What had begun as a small private film festival documentary would get its day before a national and international audience. We encouraged Michael, Debbie and Ellen to work with HBO. It was their combined efforts that gave the world "Eagle Scout: The Henry Nicols Story"[vii]. We were proud that our story was getting the national and international attention it deserved.

Participating in the making of a video documentary is a challenge. There were inconveniences in having a video crew following us, recording and documenting nearly every moment of our lives. The video crew often joined our family at many events including Thanksgiving dinner at my brother Peter's and sister in law Liz's home. It was not just Henry but our entire family that was under the inquiring eye of the video camera. It was not only a strain on us but on our extended family as well. Everyone was gracious and accepting of the challenges of making that video. They knew how important it was to all of us. There was also another issue—the physical strain on Henry. Joan and I were concerned about his health. Mike and Debbie were not only respectful of our concerns and issues, they supported us. We debated the value of the documentary and agreed with Henry and without hesitation that it was important. We all knew we were making a difference!

After the Cork Film Festival and the HBO premier, our days of AIDS activism again slowed down. Henry's health continued to fail. We could tell just by looking at him that he was losing ground. It was most obvious from his weight. He seemed to have no appetite. His already lean body was getting thinner, even gaunt.

Henry was beginning the end of his life with AIDS.

Getting Sick

Henry spent more and more time at home and more and more time sleeping. His waking hours seemed to be troubled. He didn't have any energy, and he was almost always too tired to do much. His shorter attention span made watching TV and even reading more difficult. He complained that as he read a page, he would forget what was on the previous page.

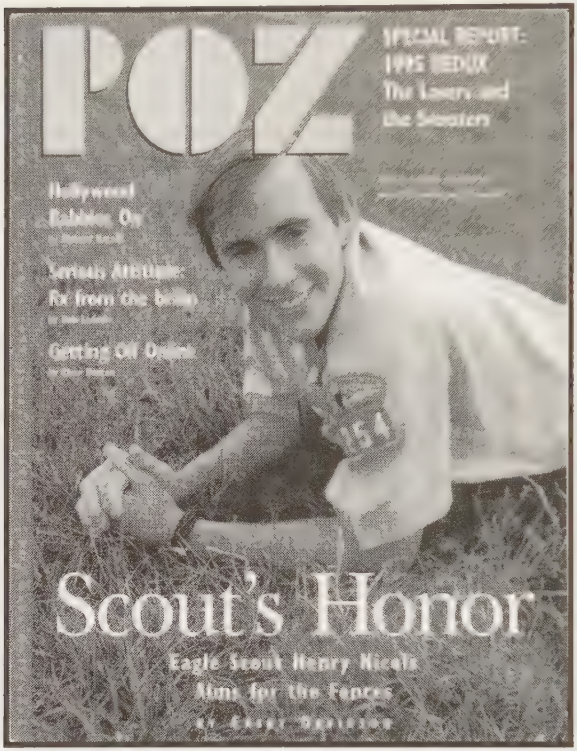
HIV and AIDS continued to take its toll. Henry was now a long term survivor of AIDS. He had been HIV positive since he was ten and had full blown AIDS for more than seven years. It was now several years beyond his predicted survival date. The progress of the disease was slow and inexorable, but steady and undeniable. In spite of his positive attitude and attempts at humor, AIDS was progressing. We were slowly losing our son.

Then Henry took a surprising turn for the better. His doctors had given him a drug holiday and took him off the anti retroviral and other prophylactic medications that he was taking. In the summer of 1996, Henry was interviewed for the December issue of *POZ* magazine.

POZ magazine was dedicated to people who were HIV positive. The readership and circulation of *POZ* were largely gay, lesbian and bi-sexual. The editors and writers of *POZ* were intrigued by Henry. Here was a white, middle class, straight Boy Scout, who spoke for everyone with AIDS. There was no anger, no recrimination and no accusation. Henry treated AIDS like a disease. He acted as though it came from a mindless, non discriminating virus. It did.

Henry became a cover boy for POZ magazine!

In his interview Henry described himself as temporarily "retired" from speaking.



22. Henry and POZ

POZ: "How have you been since POZ last spoke with you a year ago? "

Henry*:* "Well, I was hospitalized about a month ago with a urinary-tract infection, but that was only for a few days. It was basically just a couple of days on antibiotics and exciting things like that."

POZ: "How are you recovering?"

Henry: "I've gotten a lot better, but it's slow. I've lost some weight -- not a lot -- but I'm trying to get that back. It's harder than it may seem."

POZ: "What have you been doing to regain that weight?"

Henry: " I'm trying to eat and exercise a lot. It's not really any sort of regimen, but I'm not a complete couch potato. I used to do karate, but I haven't for years -- it's incredibly tiring. Mostly right now I walk. It's easy, it's not strenuous, and it doesn't hurt any body parts."

POZ: "What kinds of foods are you eating?"

Henry: "Basically just a balanced meal: A lot of meats, vegetables, fruits, good stuff. The stuff your mom always tells you to eat."

POZ: "Are you on any meds right now?"

Henry: "There are so many I don't know if I can remember them all. I take Septra to prevent pneumocisitis pneumonia -- that's something I've been taking for years. I also take Biaxin. I'm taking a protease inhibitor. And Diflucan, which is for "Thrush"; acyclovir; and some more, but I can't think of what they are. The problem right now is that I'm taking so many pills there isn't a whole lot of room left for food, and it's kind of a real pain. But I'm doing OK -- I'm still here, so I've got to be doing something right."

POZ: " Did you have to quit public speaking in order to maintain your health?"

Henry: "Well, I didn't have to stop, but I decided to stop because it's extremely tiring, and my immune system is basically gone. I mean, it's there, but they just can't find it. It's defunct. So I can get sick very easily, and traveling is excruciatingly tiring."

POZ: " How has speaking out about AIDS helped you and your family cope?"

Henry: "Speaking has helped us all deal with it. In so many ways we hadn't been able to do anything. We'd been terrified our community would find out. We didn't tell our relatives or even my doctor. Being able to get out and talk to people was very good for all of us. We've gotten a lot of practice and gotten sort of in control. I do miss it, but I'm not restless. I still try to keep myself busy. Your attitude and your mind-set have an incredible amount to do with how well you cope. If you find out you have AIDS and say, "Oh my God, I've got AIDS, I'm going to die!" then you're dead. Or you can say, "You know, this really bites. But I can still live my life."

POZ: 'Who or what allows you to keep this positive attitude?"

Henry: "My family. Without their friendship and their support, it would be impossible. It would be something I could not do. When I was doing public speaking, people would ask me what I

wanted to do before I died, and they thought I'd say, "Go to Disneyland." But I've always wanted to be President of the United States. And people always laugh at me, but I sat down and actually figured it out: You have to be 35 to run for President. I'm 23 now. I'll be turning 35 just in time for the election in 2008. And by that time, a lot of the kids I speak to will be old enough to vote. So in 2008, it's going to be "Henry for President." We're already planning TV commercials."

POZ: "Well, I'll definitely consider voting for you."

Henry: "That's good, because if you don't, I'm coming back. And this time I'm not going to be happy".

After his *POZ* interview Henry returned to semi-retirement and the long and slow battle with advancing AIDS. Gradually, he developed other problems. Walking became more difficult, and his stamina was gone. Just getting up in the morning became a chore. Showers and dressing were exhausting. Sometimes, if there were nothing special to do on a particular day, Henry would spend most of his time in bed just listening to music. Henry preferred the deep base reverberating, floor vibrating, booming, resounding sounds of music like that of Freddy Mercury and Queen.

It was ironic to think that Freddy Mercury had died of AIDS seven months after Henry announced to the world that he had AIDS. Freddy Mercury admitted only the day before his death that he was HIV positive. We often wondered how different the world would have been had famous people with AIDS proclaimed their AIDS infection without fear of discrimination. Of course, it was exactly that fear of AIDS that lead to discrimination and to denial in a potentially endless, self supporting, and self fulfilling cycle.

By the fall of '96, Henry was no longer able to walk unassisted. His balance was poor and his endurance gone. When we traveled outside the home, he preferred a wheel chair and adapted well to life on the roll. Henry in an attempt at humor named his wheel chair "Silver" after the Long Ranger's horse. We tried to fill our days and Henry's with activity. We

still took trips and traveled as though our lives were worth living because he and we believed that was the only way to live.

As Henry had said in his *POZ* interview, "If you find out you have AIDS and say, "Oh my God, I've got AIDS, I'm going to die!" then you're dead. Or you can say, "You know, this really bites. But I can still live my life."

Joan, Diana, Henry, and I took a driving tour of Grand Canyon, Bryce and Zion Canyons in the great American Southwest. We visited Las Vegas as well. We invested a small amount of money in the slot machines in the casinos of Las Vegas and, although we were limited by "Silver" the wheel chair, we lived every day as though it was important. Every day was important and made more important by the knowledge that Henry's days, indeed each of our days, are finite.

In December of 1996, Henry and I returned to the Caring Award Ceremony in Washington, D.C. As a 1991 recipient, Henry was invited to the awards ceremony that was held this time at the Frederick Douglas House in Washington, D.C. The Frederick Douglas House was an older building with several levels and no handicapped or wheel chair access from level to level. The food being served was on a different level from the level Henry and I were on. But we were where the action was and where Henry wanted to be. Henry and I agreed that I would leave him with "Silver" and scavenge for food. When I left him, he was seated alone in a corner of the room. He looked very small and frail. He was still wearing his winter overcoat because he was cold. He had lost so much weight that his clothes hung loosely from his frame. But, as usual, he was smiling.

"I will be back in a few." I said as I headed off in search of food.

"Bring shrimp!" he said.

Jane Goodall was being recognized with a Caring Award that year for her environmental and humanitarian work. Henry was excited to be meeting with her. I was, too. We liked activists. People who believe that the world can be changed are the only people who ever do change the world. Jane Goodall had changed the world. It was humbling to be in her company. Dr. Goodall, most famous for her work with chimpanzees, had studied their social and family life. From her life experience and her study of chimps, she had learned to be both a skilled verbal and nonverbal communicator.

I first saw Jane Goodall standing in line waiting for shrimp at the buffet. I introduced myself and explained to Dr. Goodall that Henry (who she had heard of from the Caring Award staff) was confined to a wheel chair. I told her that Henry was on the next level of the house as there was no wheelchair access to this level. I asked if she would come to meet Henry.

She was both delighted, and delightful. With our shrimp laden plates in hand Jane Goodall joined us on the next level of the Frederick Douglas house. Spotting Henry sitting in his wheel chair, Jane sat on the floor next to him. Jane Goodall had instantly recognized the inappropriateness of standing above a person with whom you are speaking. Henry couldn't stand, so Jane knelt and then sat on the floor beside him. As the most famous and sought after celebrity in the room, other people at the reception soon came to speak with her. Because she was sitting on the floor, her greeters did the same. In no time a large group of people were all sitting and kneeling on the floor of the Frederick Douglas House.

23. Henry with Jane Goodall

Before she sat down on the floor, no one had. Because Jane Goodall met Henry eye to eye, others followed her example. It was a powerful communication from a natural leader. Unthinking, with no

explanation requested or expected, the people at the Caring Awards followed the lead. They, like people everywhere, just needed a catalyst, a role model, a first person to demonstrate appropriate behavior. I remember thinking how different the world might have been for AIDS patients if different behavior had been modeled.

When AIDS was first identified in 1981, no one knew what to do. There was no model for behavior. Ronald Reagan was the President. Everyone worldwide was taken by surprise. The first patients with AIDS were mostly homosexual males and intravenous drug users. Reagan had surrounded himself with political and personal advisors from the Christian Right. Moral majority leader Reverend Jerry Falwell was one of Reagan's advisors. He believed that AIDS was the wrath of God visited on homosexuals. Reagan's communication Director Pat Buchannan believed and said that AIDS was nature's revenge on gay men. President Reagan, the great communicator, communicated nothing, his advisors and spokespersons communicated for him. The President of the U.S. and the leader of the free world were silent.

By 1983, more than 1,200 people had AIDS. More than 400 had died in the United States and still Reagan said nothing. In 1983 Henry was still HIV negative.

Because of administrative intolerance at the very highest levels of the White House, Surgeon General C. Everett Koop, was kept from the AIDS discussion for more than five years because of what he described as "intradepartmental politics." The President's advisors and the President himself by his own silence fostered the belief that since this was a disease of homosexuals and Intravenous (IV) drug users. They were just getting what they deserved. AIDS was punishment from God.

Reagan never publicly spoke about AIDS until May of 1987, near the end of his second term. By then the disease had spread to more than 100 countries, more than 20,000 Americans had died and more than 36,000 Americans were

infected with HIV (including Henry). I couldn't help think that Reagan the "Great Communicator" was certainly not. His sin was silence!

Ronald Reagan could have modeled a lesson from the style of Dr. Jane Goodall, but he didn't. Reagan could have spoken about the need for compassion, but he didn't. He could have chosen to end the homophobic rhetoric that spilled from the lips of his advisors, but he did not.

Reagan chose silence. Silence in those days meant delayed diagnosis, delayed treatment, and minimal research. For inestimable thousands of people early in their HIV infection or still HIV negative that silence represented discrimination, stigmatization, and death. Our president failed us. I still get angry just thinking about it.

Silence meant death, and it was inexcusable.

Henry's Girlfriends

Henry received his first invitation to marry before he became famous in the *Parade Magazine* article. The proposal came while he was in first grade. A young woman we know who still lives in Cooperstown proposed marriage, and Henry accepted. Alas, as it is with so many star-crossed lovers, it was destined not to be. While that was Henry's first love, it was not his last.

Because the young women in Henry's life have grown to have their own lives and because there is still a stigma associated with AIDS, and because this is not that kind of a book, I will not describe the relationships that Henry had from first grade on. Suffice it to say that Henry had girlfriends through school and after.

Henry maintained good relations with many of his girlfriends long after their dating relationships ended. Very early in his pre teen life, we had discussions with our son, as we had with our daughters about the need for them to understand the complexity and importance of human sexual behavior. We discussed the importance of safer protected sex and the proper use of condoms in any sexual relationships that they might have. For Henry there were added complexities. He knew very well about universal precautions and the need to not have any blood or body fluid exchange because of the risk of transmitting HIV / AIDS.

Henry had two serious relationships with young women that we knew about. On one occasion, he spoke with Joan and me about that relationship. Like any son, he spared us the details and specifics of his relationships but as it got more serious he had questions. He and she were discussing marriage. Henry wanted to understand what would happen to his health insurance coverage if he were to marry. As best we could, we discussed the serious ramifications of having and not having insurance. We talked about the potential financial burden to be shared by a spouse in a marriage where one partner has a

chronic and expensive illness like Hemophilia where there was a need for transfusions of expensive blood products. The financial strain of chronic illness in general and of Hemophilia in particular has devastated many marriages. Then there was the additional issue of AIDS.

From the time we left the Army, Joan and I always had excellent health insurance. Both of us maintained separate insurance policies that provided comprehensive coverage. As our dependent, Henry was covered under our two insurance plans. Even with two insurance policies many things were not covered by insurance. Joan and I were under a constant strain to pay deductibles, incidentals and extras related to his health care.

Once Henry became old enough to legally emancipate from his parents, he was able to file for Social Services Supplemental Medical benefits. He had no money and because he was unable to work due to his failing health, his insurance coverage actually worked out better for him without his parents in the picture. Unfortunately, the way the system worked, if he ever got a job, or if he ever married and had a spouse with money, he would be expected to pay for the benefits he was now receiving for free. The cost of the benefit might exceed the income from the job or the potential income of a wife with any but the highest paying jobs. The system dictated that even if he could work, it didn't make sense for Henry to get a job. It did not make financial sense for Henry to marry. He and his wife might end up working just to pay for his healthcare.

About the time Henry and his significant other were talking about marriage, he became more seriously ill. His physical and mental capacities were diminishing. It became obvious to us and to both Henry and his girlfriend that their thoughts of marriage and leading a normal life were just a dream. It was a dream that, like so many others, would just evaporate into the mists of confusion, complexity and the tragedy of AIDS.

In time, the young woman he loved and who loved him drifted away. It was painful to both of them. It was painful to watch.

Winding Down

Henry knew he did not have the stamina to return school after his speaking tour as he had planned but there were several times that Henry attempted to be self sufficient and work. He got a job working in the Medical Records Department of Bassett Hospital but his health issues and high absence rate made it impossible for him to maintain any regular job.

In 1998, we were noticed a steady but significant impairment of Henry's physical and mental functions.

He had balance issues when he walked. He developed an awkward gait with his feet spread wide apart, almost like a sailor on a ship or a cowboy just getting off a horse. Henry had also developed some repetitive physical habits. He was constantly wringing his hands or tapping his feet. These repeated hand motions caused him to develop callous knobs on this thumbs from the hand wringing. But the single most concerning issue to us and to Henry was that he seemed to not be as mentally sharp as he had been. His long term memory seemed intact but his judgment, executive functioning, and his short term memory were all failing. I think the single worst thing for Henry was that he knew and understood that he was losing his abilities.

Fortunately, some of the long term memories and other skills remained intact. On good days, Henry was still able to leave the house on his own. He especially enjoyed driving his car, a sporty Pontiac Fiero with a great stereo. Usually his stereo was cranked as loud as it could go. Mike Foltzer, one of Henry's doctors, lived just a few miles up the road from our house.

Mike once said to me, "I can always tell how Henry is feeling when he drives past my house. If I hear the Meat Loaf song 'Paradise by the Dashboard Light' I know that he is OK."

Mike was right. There was a direct and observable relationship between how Henry felt, how mobile he was in his car, and how loud the volume on his stereo was turned up. Shortly, after Mike made that comment to me, Henry was out for an afternoon on a beautiful spring day. Joan and I were home working around the house, doing one of the hundred spring cleaning chores left over or delayed by the deep snows of our New York winters. The portable phone sitting outside on the deck rang. I answered; it was Henry.

"Dad, I am at Stewarts store in Cooperstown." Henry said. Stewarts is a gas station and a convenience store on the main street that enters the village. It was seven miles from our home.

"And...." I said, expecting him to ask if we needed anything or if we would mind if he stayed out longer. I was not expecting what he said next.

"I don't remember how to get home?"

He sounded defeated.

"Stay right there. We are coming to get you!" Joan and I left immediately.

The next day found us in the hospital. Joan and I were meeting with some of Henry's doctors. He had already signed a power of attorney and a healthcare proxy that entitled us to represent him in his legal affairs and in his health care issues. Henry was getting yet another MRI. Magnetic Resonance Imaging is a technology that had recently developed and has greatly improved in the last decade. Similar to an X-Ray, but far more sophisticated, the MRI allows physicians to take a three-dimensional look at the human body without doing any surgery. Henry had MRIs before, for many different reasons. Today's scan would be compared to a head and brain scan that had been done a few years before when we were looking for evidence of a bleeding episode in the brain. The doctors thought that the comparison might be revealing. It was.

The radiologist reviewed the MRI films with the three of us. He pointed out the subtle differences that even our untrained eyes could see. Henry's brain showed clearly in the images and the spaces in his brain were larger. His brain was quite literally shrinking.

"The Human Immunodeficiency Virus is one of the viruses that can cross the blood brain barrier." The doctor explained to us. "It looks like Henry is developing AIDS-related dementia."

We knew about AIDS-related dementia. We just hoped that we would never see it. Fortunately, Henry's dementia was still in the early stages and not yet profound. Although the symptoms of AIDS dementia are similar to Alzheimer's disease, they are not the same. The causes, diagnosis, and treatment are all different. AIDS related dementia is treated by focusing on the underlying HIV infection, maintaining the patient's physical condition, and avoiding stress. At that time, no medications to treat Alzheimer's were available but there were some that might delay or minimize the effects. Both diseases are managed by supporting the patient as much as possible. Routines, familiar places, and familiar people bringing consistency are all important in the management of dementia.

Significant similarities and unique differences exist among the AIDS patients who present with dementia. Henry had good days and bad days. On good days, it was often difficult to tell that there was any impairment. On bad days, it was painfully obvious that he was losing his cognitive abilities.

We could still leave Henry at home alone. He was able to care for himself provided he was reminded to change his clothing, brush his teeth, and avoid getting into trouble. Sometimes he was ingenious at figuring out new and different ways to get into trouble. We were all on constant alert.

After this latest MRI test and as the new realization started to settle in that Henry now had a decreased mental ability, I contacted a friend and colleague, Susan Baum. Susan and I had

met at a conference where we were both presenting. I knew that Susan was one of the world's foremost experts on twice exceptional children. Her Ph.D. was earned by researching and working with children who are both gifted and in some way are also learning disabled. She is the author of numerous books and articles concerning special needs children. She knew about Henry and agreed to meet with him. Susan suggested that we have Henry tested so that she would have some basic information about his limitations and abilities. At Susan's suggestion, Joan took Henry to Storrs, Connecticut, home of the University of Connecticut to meet with Miriam Cherkes-Julkowski, Ph.D. Miriam administered a day-long battery of tests and then submitted a detailed report to Susan and to us. Miriam's test confirmed what Joan and I were seeing in our son.

He had an above average intelligence, superior verbal ability, and a unique sense of humor. Henry was also having obvious trouble with executive functioning, decision making, and handling many proximate details. Miriam was unable to tell us the cause of his problems but agreed that AIDS related dementia was a likely culprit.

Susan and Miriam both gave us advice and a few recommendations. They suggested that we stop trying to focus on what Henry could not do and instead focus on what he could do. They suggested that we needed to provide a 'scaffold-ed" environment where Henry would be supported in doing the things he was able to do. They also both suggested that we would get along better with our son if we could focus on his talents and strengths.

It was hard; no, it was very hard, but we tried.

Henry tried too. He got a job at a local Wal-Mart Store working as a greeter. Wal-Mart's was wonderfully supportive. They recognized Henry's health challenges and impairment and they accepted him and made accommodations for him. Henry's health and short attention span made it difficult for him and them. He was unable to maintain a work schedule. He just couldn't keep a job.

Sometimes Henry had a unique knack for getting into trouble, and it could be humorous. Once he called me at work and offered to help out by making dinner. Joan and I were both working. Henry wanted to do something nice for us, and at the same time, do something to occupy his time with the little energy he could muster.

When we came home that evening, we found that Henry had prepared carrot / sesame salad. That was it—carrot salad, six pounds for three people, nothing else. Henry had shredded every carrot he could find in the house and had made nothing else. Although it was delicious and very healthy, it was a dinner we will remember forever but not for its culinary appeal!

Susan and Miriam's advice warned us that, if we wanted Henry to make dinner, we needed to provide him with a menu, a list of ingredients and recipes, and a time frame in which to work. It actually did help. Scaffolding and focusing on strengths and talents enabled us to get by some issues that could have been even more devastating if we had only focused on the things he couldn't do.

Sometimes Henry's getting into trouble was not humorous. Henry's genetic code carried not only the DNA and gene for Hemophilia, but he descended from a long line of honest, alcohol-abusing people on both his maternal and paternal family trees. Both of Henry's grandfathers were recovering alcoholics, and some of the relatives from both Joan's and my side of the family have had continuing problems with alcohol. Alcohol abuse was not a new issue to us. In our family, many of the people know the code words for "I am an alcoholic." In case you didn't know, it is "I am a friend of Bill." It is a common reference to being a friend of Bill Wilson, the deceased founder of Alcoholics Anonymous.

Joan and I knew that, according to the National Institute for Health, nearly 10% of the population meets the criteria for alcohol use disorder. Even with that knowledge, alcohol abuse

by our son was a new and unexpected issue for us. Alcohol was an issue for Henry.

Although Henry was then twenty-six years old, working with him was more like managing an adolescent than an adult. He had previously liked to drink, but his drinking became more and more problematic and more frequent. One of our first strategies was to limit the alcohol available in the house and to restrict his drinking to our home. Henry was fairly compliant. At first it was not a big issue. It would, however, become worse with time.

As the months went on, Henry seemed more depressed and became moody and sullen. Then, one day, he approached Joan and me. With no apparent specific emotional trigger and no special provocation, he said that he thought he was depressed. We asked Henry to explain what he meant.

"I have had AIDS a long time, and sometimes I don't know how much longer I can go on." Henry explained that he no longer felt like he could control his emotions and feelings and perhaps his temper. He was sad or angry all the time. He was afraid that he might hurt himself.

We asked him if he thought that he needed to be in the hospital. He said that he did. That was Henry's first psychiatric admission. We took him to the emergency room and, after being interviewed by the Emergency Department physician, Henry was sent upstairs to the second floor north inpatient psychiatric unit. He was a voluntary admit who needed to be hospitalized. The psychiatric unit was much different from any other unit where we had ever placed Henry. It was a locked unit.
Access was controlled by the nursing staff. Visitors, including parents, could not come and go as they pleased. Henry was in seclusion. Although it would have been possible for him to sign himself out against medical advice, it was the first time in his life that we and he could not come and go as we chose.

Henry was in the hospital about ten days on that admission. They added some new drugs to the "witches brew" collection of

medications that he took for his HIV infection and as prophylaxis for the myriad of illnesses he was susceptible to getting. Over the next few months and in rapid succession were several other brief psych admissions and outpatient counseling sessions. During the inpatient stays and outpatient visits, we all attended counseling together and separately. The joint decision was made that Henry should be given the opportunity to live in a group home for adults with AIDS.

One weekend in late 1999, we moved Henry into the AHANA House in Waterford, New York, about 85 miles from our Cooperstown home. AHANA is an acronym that most often means **A**frican, **H**ispanic, **A**sian, or **N**ative **A**merican and may have been first used by a group at Boston University who disliked describing people being served with "Minority Programs." So AHANA replaced the word minority. When I asked, I was told that AHANA was an African word that means welcome.

The AHANA house, established by a philanthropic group called the Support Ministry for Persons with AIDS, was a God send to us. It was a co-ed adult home for people with AIDS or other issues. The people who lived in the AHANA house supported each other and, with the help of a small staff, lived fairly independently. The building itself was a very large, older, one-family home with private rooms sufficient to house a small community of about 15 people.

It reminded me a lot of the living arrangements in a fraternity or a college housing community. The rooms were small and fairly Spartan with enough space for a bed, a dresser and a closet. There were a common living area with a television and a common dining area. Food was adequate but not exorbitant. There were only a few rules. One required that there be no drugs, including alcohol. Individuals had to abide by the rules of the community, no excuses!

But most important was that Henry was welcome there. This safe haven gave Henry and us a much needed respite from each other. Henry liked the AHANA house, but not enough to

want to stay there. He preferred his room in our home. He preferred his mother's cooking and his own television. He wanted to come home again to live with us. Almost every weekend we would either come to get him, or he would beg a ride to Cooperstown from one of his sisters.

Although we missed our son terribly, we insisted that he stay at the AHANA house as we had negotiated with his mental health counselors. Joan and I thought it important for Henry to try living on his own. And, frankly, we needed the rest. It was overwhelming to have an adult child with AIDS who had mental health and alcohol issues living in our home.

Henry was in the AHANA house only a few months when his health, both mental and physical, and his spirits seemed to improve. He seemed so much better that we began to slowly allow him to drive again. At first Joan or I would drive with him. Then, gradually, as he progressed, we returned his privileges. He was getting better. We were pleased. So was Henry. However, Henry did not like being away from home and still wanted to return to our home. We continued to believe that staying away from us was good for him. Then, after a weekend visit to Cooperstown, he returned to the AHANA house intoxicated.

He had violated the rules and was asked to leave. No excuses! Joan and I drove to AHANA to bring Henry home. He seemed appropriately contrite, but he was glad to be home again. Perhaps he won.

On the way home from AHANA house, I read Henry the riot act. I told him how disappointed we were in him and how he was running out of options. He was 27 years old and incapable of living on his own because of his obvious and now readily apparent and acknowledged physical and mental disabilities. Yet he insisted on making it impossible for him to live with us or to live on his own in a supported environment. We told him that he was running out of options. We would agree that he could return to our home as long as he followed the basic rules of our family.

We made these essential agreements:

1. There would be respect -- for him and for us.
   - We would respect his need for sleep and privacy.
   - He would also respect our need to have him participate in family functions. We would expect that he attend family functions with his mother and with me and participate in occasional Scouting trips with me.

2. There would be safety.
   - He could drive only with our permission providing he revealed where he was going and when he would be home.
   - The only alcohol in the house would be provided by Joan or me and could only be drunk in family areas in the evening in the presence of another adult.
   - Never would drinking and driving be tolerated.

3. There would be responsibility.
   - Henry would do chores as assigned and would be responsible for his own personal chores like laundry and cleaning up after himself.
   - Henry could take charge of meals in advance if a menu was prepared. (No more six pounds of carrot salad, please!)
   - We would be sensitive to Henry's energy levels. Henry could sleep in on days when no other activity was scheduled.

4. Finally, and perhaps most important, we would continue to have fun and to enjoy each other's company.

Early in 2000, things seemed on an even keel and appeared to have calmed down. But Henry continued to have some health difficulties. He was losing weight and energy and sleeping more and more. When awake, he was fairly subdued.

The combination of fatigue and medication meant that Henry was driving less and less. We made fewer and fewer demands on him. Alcohol no longer seemed to be an issue. It seemed as though Henry was too tired to get into trouble. It was not a bad thing for him to be exhausted.

Joan and I were concerned about what the future would hold for Henry. He was an adult in age, physical stature and experience while his physical abilities and mental capacity were child like. He was often unreliable in decision making and in foresight. We struggled with alternatives for our adult son. We believed that it was necessary for his basic human dignity to treat him like an adult. Yet we were concerned about his capacity and potential for getting in trouble.

This was one more thing that we had not prepared for. We never thought that Henry would live long enough for us to have to worry about what he would do as an adult. We never expected the limited physical and mental abilities with which Henry was now living. AIDS related dementia was not anticipated as a possible complication.

With Henry's consent and willing cooperation we decided to explore options. We came up with the idea that Henry and Joan could work together.

In an ideal world Henry needed a social setting where he could interact with other people. He still loved talking and telling stories, but his executive functioning was so severely limited that he was unable to make decisions on his own. Joan more of an introvert did not seek social opportunities but could contribute to their business relationship by being the supervisor, coordinator and of course and most importantly, Henry's mother. Surely our tourist rich environment of Cooperstown and the National Baseball Hall of Fame would provide some opportunities that we could identify.

We actively sought places where we could have a sheltered workshop that Henry could operate as a contributing adult and still be in a protected environment. Joan and I interviewed people who were selling their businesses.

We looked at vending machine routes where people supplied goods and services to physical locations by driving from place to place. We decided that there was not enough social opportunity for Henry.

We considered buying a laundry with washers and dryers. That business would require someone to service the machines, clean the facility, stock the change machines, and manage the business. We decided that opportunity did not have enough personal interaction for Henry. He needed contact with people.

We considered investing in a small restaurant / diner where Henry could work as a short order cook in the kitchen and serve as an all around waiter type of person. He did love to cook and with the proper structure and scaffolding he might be able to thrive. Joan could run the business and manage the planning and the operations; Henry could do all of the people interactive duties and had the nearly perfect personality to be a short order cook. He could entertain waiting diners at a restaurant counter with his stories while flipping burgers and making fries. After careful consideration we decided that owning a restaurant, even a small one would be more work than Joan and Henry wanted to do. We scrapped that idea as well.

However, Henry really liked the idea of working in a restaurant with the intention of owning his own business even if it had to be structured and protected. With that idea in mind Henry decided to go to cooking school. With the help of the local Board of Cooperative Educational Services (BOCES) Henry enrolled. Joan and I supported this decision. We thought it was good to occupy his time with the academic part of school. Henry enjoyed cooking and being with his classmates learning the finer arts of working as a chef.

Joan and I continued to look for business opportunities where she and Henry could work together. Our plan was to find an opportunity for Henry to maintain his dignity. He still

needed to be a contributing adult in a sheltered environment. We were prepared to do nearly anything. Joan would give up her career, and I would support them in whatever our new business would be. It would give Henry an opportunity to function as an adult.

While Henry was in cooking school, Joan and I observed once again that he did not have the stamina to do things on a consistent level. He was often too tired to go to school even though he enjoyed the idea and the socialization; the physical demands were just too great. Henry was exhausted.

Joan and I were exhausted too. As parents you try to make things right for your children. You provide as best you can, give as much as you can, and hope for the best. Small children often believe that their parents can fix anything. Sometimes parents believe it too. As children mature they begin to understand that their parents are only human and many, many things are out of their control.. Jennifer spoke of that childhood revelation in the documentary. She described how she had once believed that Mom and Dad could fix nearly anything. When the realization came that there was nothing more that we or she and Diana could do for Henry, it was an uncomfortable truth. There is a time when you need to decide to understand that love can't fix everything.

Sometimes we can't even make things good for those whom we love. The best we can do is to love them, to be with them, and to be there for them. So it was with Henry. There was nothing more to do. There was nothing for him to do and nothing more for Joan or me to do.

In April of 2000, Joan's entire family gathered to celebrate the 75th birthday of her mother Rosemary. It was an O'Donnell family big deal. Each of Rosemary's seven children gathered at their childhood home to spend time with the matriarch. Our family gathered on the front steps of the house for a family portrait. Rosemary sat at the top of the pyramid and then sitting below the rest of our family gathered. We did not realize that the photograph that we took that day would be the last ever photograph we would take of our son.

The Accident

His doctor felt that Henry needed a break from some of his medications. For the second time in his life Henry was given a drug holiday. Taking him off of his drugs was dangerous as it gave the AIDS virus a chance to spread even more, if that were possible. Henry would be susceptible to a wide variety of opportunist infections. The plus side of the drug holiday was that off his medications Henry felt better. Soon after his drugs were stopped Henry was able to drive again. About three weeks later, on Friday, April 28, 2000, Henry was driving to pick me up at work. The two of us had plans go to a Scoutmaster training program at the local Scout camp where Henry and I would be instructing new Scoutmasters. My Scout uniform and boots were in the car when he pulled out of our drive way onto County Route 31. The road south of our house was under construction where a bridge was being replaced causing long delays. Henry decided to drive the long way into Cooperstown. He headed north. Henry would not have minded going the long way around. It was a beautiful day. The sky was blue and the sun was shining. Crisp, white, fluffy clouds floated above drifting on a gentle spring breeze. As Henry drove north past Mike Foltzer's house, his music was blaring. He was playing *Queen*. He felt good. We don't know why, perhaps inattention, perhaps speed, but for some reason the right front tire of his sporty Fiero drifted to the east edge of the road way.

County Route 31 is a narrow, two-lane road with deep ditches to divert rain runoff on both sides of the road. If you land in the ditch, you don't easily drive out without a tow truck. Henry's right front tire edged off the road and slipped into the ditch. Henry tried to drive out of the ditch and continued on about 150 feet. The right front tire still in the ditch then struck a culvert. As the tire hit the culvert the tire left the ditch and the car bounded of the ditch, crossed the road and struck a tree on the opposite side of the road.

We don't know who called 911. Joan and I do know the rescue squad volunteers who responded that day. They were our neighbors. They knew Henry. He was delivered by caring hands to Bassett Healthcare in serious condition. He had been wearing his seat belt and had seat belt injuries from the sudden impact stop. As he was removed from the car, bruises across his chest and lap from the seat belt were already painfully visible. He had head and facial injuries from where he hit the steering column and the dash as it collapsed into the passenger compartment. Other injuries were more difficult to see.

Joan and I were together waiting for Henry to pick me up from work to leave for the Scout trip when the call came into my cell phone from the hospital emergency room. Henry had requested that we be notified and the Emergency Department Manager, Laura Kasey shared what she knew. Henry had been in a serious car accident. They needed us in the emergency room STAT.

Joan drove our car and dropped me off at the emergency room entrance where Paul Bedworth, who also worked at the hospital, was waiting on the lawn to meet me. After dropping me off and without stopping at the hospital, Joan drove home to get the blood concentrate that we had there. It would be faster to give Henry the Factorate ™we had at home than to wait for the hospital to order more to replenish the small supply they kept in stock.

I went in to the emergency room. Henry and the ambulance had just arrived. He was being unloaded into trauma room number one. It is the first room on the right as you walk through the automatic glass sliding doors.

"Hank! It's bad!" Laura Kasey said as I rushed into the emergency room. Laura Kasey, the head nurse, was a family friend. We knew her from our frequent visits to the emergency room.

"How bad?" I asked.

"Very." she said.

The emergency room seemed even busier than usual as nurses and doctors rushed around in their frenetic and seemingly chaotic choreographed dance of life. Henry was still awake, alert, and conscious. He was joking with the nurses about how many bloody gauzes they could put in and then pull from his mouth. He was being readied to be rushed out of the trauma room after being stabilized so he could be sent to the CT (Computed Tomography) room where the exact nature of his injuries could be better identified.

I went into the room to see Henry before they took him away. It was just for a few seconds. I held his hand and told him that I was there. He looked up at me.

"I think I totaled the car," he said as he looked up at me from the hospital gurney through the thick bandages that wrapped his facial lacerations. The fresh blood was already soaking through and staining the clean white gauze bright red.

"It doesn't matter, about the car." I said.

"Where is Mom?" he asked.

"At home, picking up the Factorate ™," I said.

Henry understood immediately. Joan was always the practical one. Whenever something needed to be done, she was the one to do it. The hospital would need his Factorate ™ before doing any surgery. It was logical. It was necessary. It was typical Joan.

"Tell her I am OK," he said.

Then he again teased the nurses about how many gauzes they could fit in his mouth. He was having trouble speaking

through the pads, which were being used to soak up the blood that seemed to be draining faster than the gauze sponges could collect it.

"We have to go now!" the CT technician said, stepping on the wheel release and tugging on hospital gurney.

"I love you, son. Hang in there," I said.

"I will, I love you guys, too!" Henry said through his blood-soaked gauze-filled mouth.

Joan arrived only minutes later and was shortly followed by our daughter Diana, who arrived in her police uniform. She was on duty at the police station when she heard the news of the accident. Diana was joined by her significant other Mark diLorenzo, a deputy sheriff and former police officer from Oneonta. They had driven to the hospital together.

In what seemed like hours, but I am sure was only minutes, Dr. Frank Zimba, one of the hospital's three neurosurgeons, was meeting with us in the emergency room.

We knew Frank and his family. His son, David, was one of my Boy Scouts. We knew Frank's reputation, too. He had a history of being short and sometimes abrasive to hospital staff. His surgical skills were excellent, and he was a first rate patient advocate. I always thought that his patient advocacy gave him the reputation for being short with the staff. He did not suffer fools or incompetence easily, especially when it came to his patients. He was exactly the type of neurosurgeon I wanted for my son.

"You have to decide," Frank said. He knew that Joan and I had a health care proxy for Henry and were empowered to make the decisions regarding his treatment. "Henry has a serious brain injury. There are several other injuries as well. His jaw is broken, his leg may be broken and he has some internal bleeding and injuries as well. The most serious and life threatening injury is to his brain."

Frank was reporting to us crisply and matter of fact.

"Dying of brain injuries like Henry's is not a bad or an unpleasant death. We need to decide right now to do surgery or not. If he survives the surgery, there is a chance he will be brain injured and will suffer the effects forever. There is also a chance that he will never fully wake up from the surgery again. There is a chance that he will live and recover, but how well he will recover I have no way of knowing. If we don't do the surgery now, Henry will be dead within a few hours, perhaps less." Frank was not taking a lot of time for bedside manner. Henry did not have the time. I was glad that it was Frank Zimba!

"I am not sure that we can save him, but I can promise you that if you want we will do the best we can," he continued.

His promise, although hedged, was all we had.

"This is going to be hard on your family. Henry's recovery, if he recovers will go on for weeks, months, possibly years, and you have to decide now." Frank repeated.

Joan, Diana, and I looked at each other and realized we had no choice. We had lived nearly all our family life in the difficult mode of responding to choices that no one should ever have to make, for which no one asks for and can ever be prepared. We did not ask for Henry to be a Hemophiliac. We did not want it but did what we had to do. With AIDS, clearly we did not ask for or want it in our lives. We responded as we had to. It was the same now with Henry's brain injury. There was no choice.

"How soon will you start?" I asked.

"Now!" Frank replied.

Joan and I went into the trauma room where Henry was being prepared to be taken to the surgical suite. We explained to Henry that he was going to be taken downstairs so they

could fix the bleeding in his brain. We held his hand as Joan told him,

"You are going to be OK! We love you."

Henry replied. "I love you, too. And you will be OK, too!" It was the last thing he said to us. In an instant, he was gone, down the corridor to the elevator to a waiting operating room.

There was nothing for us to do. We chose the hope of life, just as we had done at every juncture in our lives before. Everything we had done before prepared us as best we could be prepared for this impossible moment.

Joan, Diana, and I were still in the hospital surgical waiting area when Jennifer and Todd arrived about an hour later. Our family was all together. Henry was one floor below, in surgery.

While we waited for Henry to get out of the operating room, we did what our family did best. Through frequent tears and hugs, we made a plan to manage the next few weeks.

We knew that Henry would be going to the Intensive Care Unit and we knew that hospital patients with family members in attendance received better care. Fewer nursing and medication errors occur, and patients have a faster recovery. So we made a schedule.

We also knew that it would be impossible for each of us to be present all the time. We agreed that for the sake of sanity, we would all need rest. We developed some basic ground rules. During the day time any immediate family member would visit as they choose, but at night only one family member would be present at a time. That family member could not stay overnight again for two days. This way each of us could take turns staying with Henry during the days as we were able and at night one of the four of us would always be with him. It was a good plan. It turned out to be very important. As the neurosurgeon Frank Zimba had promised, we knew it was not going to be easy. It was not.

The next eleven days were a combination of blur and a very bad dream. The surgery was unable to stop the bleeding from Henry's multiple injuries or into his brain. His coagulation and clotting difficulties, always complicated, were now nightmarish. Years of AIDS supporting drugs had damaged his liver causing his blood coagulation condition to be unmanageable. His laboratory tests were a study in laboratory abnormality. Nothing was working in his body as it should have.

Immediately following his surgery, Henry was transferred to the intensive care unit. He was on a respirator. He was unable to breathe for himself. He had feeding tubes, catheters, and drains from every orifice in his body including those formed at some surgical sites creating internal access where none normally exist.

With the recommendations of his physicians, we made the decision to delay repair of his broken jaw and his broken leg until he was in better physical condition. Attending to minor injuries, when so many life threatening issues remained unresolved, seemed pointless.

The day following his car accident, Henry was returned to the OR for a second brain surgery when a follow up CT scan showed more unresolved bleeding in the brain. A tracheotomy was performed to better ventilate him. More drains were inserted. More blood was pumped in.

Henry's kidneys and liver started to shut down. In spite of the prescribed diuretic drugs used to help the body remove fluids, Henry, who could not gain weight for years, gained it now. In ICU in just days he went from 140 pounds to 220 pounds. He had more than 80 pounds of fluid built up in his tissues. His face, abdomen and body looked as though he had been inflated with air. His heart struggled to keep the fluid in his arteries and veins in circulation.

Henry was on a constant morphine drip for pain. When the morphine levels were lowered, he showed symptoms of pain

and discomfort. Although he was never conscious, Henry remained aware of pain stimulus. When poked with a pin, he would withdraw from the site of pain. That was a good sign. It showed that his brain was still functioning.

There was another good sign. For brief periods each day Henry was removed from the respirator. Although it was difficult, he was able to sustain some breathing on his own. Each time the respiratory therapist disconnected Henry from the respirator, we anxiously watched the monitors that showed his blood oxygen levels. When left to breathe on his own, his oxygen levels decreased but this was part of the process. As challenging and worrisome as it was to disconnect him from the respirator, it was important. Hopefully one day the doctors would be able to remove him from the respirator, but many patients, especially those with AIDS who are connected to respirators, die of Acute Respiratory Distress Syndrome or ARDS. ARDS was just another threat in a long list of things that could still claim Henry's life, especially now that he was weakened not only by AIDS but by his multiple injuries.

After ten days of our maintaining an almost constant vigil at his bed side, we made the decision that Henry could spend the night alone in the care of the on duty intensive care nurse. Jennifer and Todd returned to their home about seventy-five miles away. Diana returned to her routine work schedule. Impossible as it might even be to imagine, we were all settling into yet another life and death reality. Henry was in extremely critical condition. Already we were adapting to the new reality. Intensive care had become the new norm.

On May 6th Diana and Joan talked me into going to the annual Boy Scout awards dinner in Oneonta. It was subterfuge on their part. I had recently given the entire family a speech about living our lives as normally as possible while Henry was in the hospital. They used the line on me. The plan, as they presented it to me, was to leave Henry earlier that evening in the care of the ICU nurses and to go to the dinner. We would sneak out early during the awards to return to the hospital. When we got to the awards ceremony, Tom Wright, our Council Executive asked me to present the training awards. As the

training chairman, it made sense to me. The subterfuge continued and much to my surprise I was awarded the Silver Beaver. It is the highest award a Scout Council can give to an adult. I was sincerely honored. The night was made even more special because so many of Joan's and my friends from the Scout troop attended the award ceremony[2]. They were all in on the plot with Joan and Diana. It was a very much appreciated break from the crisis of the last week and a refreshing reminder that life continues in spite of the challenges of the moment.

Things seemed calm.

Then early in the morning of May 8th Joan and I were sleeping at home when the phone rang. It was about 5:30 A.M. Early, early morning phone calls are never a good sign, and we were both instantly awake. It was the intensive care nurse. Henry had been agitated during the night. As he thrashed about, he pulled out his nasal feeding tube. He had aspirated some stomach contents into his lungs. His breathing, which had been improving had now become problematic. It was more difficult and labored.

There is a medical term that is discouraged by professional healthcare providers. It is disrespectful, and callous, but accurate. The term is a "train wreck". Henry was a train wreck. No professional healthcare provider would ever say that to a patient or to a family member. But speaking in code to each other, with their guard down, they might have said what we knew. Henry was a train wreck.

There was too much wrong. He had prolonged bleeding in the brain. He had broken bones, uncontrolled internal bleeding, no clotting ability, liver and kidney damage and tissue damage from fluid build up. To complicate issues even more, he had

[2] Attending the award ceremony with us were, Bill and Jean Cramer, Tony and Sydney Scalici, Pete and Judy Henrici, Frank and Ann Capozza, Ron Cramer, Gerry and Suzanne Bers, and Joan and Diana Nicols.

aspirated material into his lungs and had redeveloped what had been a resolving pneumonia. Henry was having trouble breathing. The end of his life was near.

Joan and I called the girls. By lunch time, Diana, Jennifer and Todd were with us in the intensive care room. Father Roos our pastor from St. Mary's church came to the hospital and administered the Catholic sacrament of the sick.

As the afternoon progressed, we took turns talking to Henry, touching him, reassuring him that we and he would be all right. Gradually, his blood oxygen levels dropped, his heart rate increased and then slowed. Finally, in the presence of those who loved him longest, his father, his mother, his sisters and his brother-in-law, Henry slowly, quietly, and peacefully died. It was 5:22 P.M. on May 8, 2000.

It was raining outside.

The Wake & Funeral

The wake for Henry was held in the largest of the Cooperstown funeral homes. The line of family and friends was non stop and out the door for all of the two days of calling hours. The parking lots were filled to over flowing. The family was besieged with supporters who shared messages of love and comfort.

In the funeral home, cards were given out with a painting of the Mother of Jesus, the Virgin Mary, on one side and on the back were the dates of Henry's life and this poem.

Do not stand at my grave and weep:
I am not there, I do not sleep.
I am a thousand winds that blow:
I am the diamond glints on snow.
I am the sunlight on ripened grain:
I am the gentle autumn's rain.
When you awaken in the
morning's hush,
I am the swift uplifting rush
Of quiet birds in circled flight.
I am the soft star that shines at night.
Do not stand at my grave and cry.
I am not there: I did not die.
Author Unknown

Henry's Funeral Mass was conducted at our church, St. Mary's, in Cooperstown. Although I don't remember much of it, there were moments of exceptional clarity.

I remember that Henry's friend Michael Henrici, one of our Boy Scouts who had hiked and camped and visited with Henry in the hospital, spoke emotionally and eloquently about Henry being like an older brother to him.

"Henry was the older brother I never had," Michael said, tears welling in his eyes and his voice strained with emotion. "He's not gone as long as we remember everything he taught us." Michael had trouble finishing his words. I am so proud of Michael, I was unable to speak at all and wouldn't even try.

Andrew Hildebrand, another Scout and close family friend who had flown from Florida with his father Robert to attend the funeral service, spoke, too. Henry had met Drew and his brother Greg and sister Katherine in Germany when they were all children. Henry entertained them all with scary campfire stories, which is what Drew remembered and retold.

Sara Albright, a family friend and a colleague from Bassett Healthcare, has the voice of an angel. At our request Sara sang at the funeral. The first hymn was the Prayer of St. Francis, which seemed especially fitting and in part says,

Lord, make me an instrument of Thy peace;
where there is hatred, let me sow love;
where there is injury, pardon;
where there is doubt, faith;
where there is despair, hope;
where there is darkness, light;
and where there is sadness, joy.

Sara's song was metaphorical for Henry's Eagle Scout project and his mission about AIDS. It was metaphorical for his life.

Joan's second requested hymn was again connected to Henry by the fates. She chose "On Eagle's Wings."

And He will raise you up on eagle's wings,
Bear you on the breath of dawn,
Make you to shine like the sun,
And hold you in the palm of His hand.

I don't know how Sara got through the songs. Many in the congregation cried.

Father Roos, church pastor, who had visited with Henry shortly before his death spoke about mountain climbing and connected Henry to 2000 thousand years of Catholic tradition.

Next was Jennifer's Eulogy for Henry. I was surprised to discover that Jena could think and talk. I just couldn't get words out, any words. I spent the funeral standing with Joan and holding my granddaughter Victoria. I held Victoria especially tightly as her mother spoke.

"Henry was twelve when our family found out that he was infected with HIV. No one could tell us what would happen. Some doctors had bad news. They thought that he would get AIDS and die right away. Other doctors were more optimistic. They said that he would probably get AIDS and die in a few years. Back then living with AIDS for any amount of time was practically impossible. Henry used to joke that he had the life expectancy of a hamster.

Finding out that Henry was infected with HIV changed our family forever. Overnight Henry became like Peter Pan, the boy who would never grow up.

It was a tragedy then, and it is a tragedy now.

Over the years we as a family and a community have mourned all that Henry would miss: the chance to get married, to raise a family of his own, to someday have grandchildren to spoil. The chance to be an adult; the loss, especially now, when it is so fresh, seems overwhelming and senseless.

We console ourselves and each other with the knowledge that during his short life, Henry touched the hearts of millions. He brought understanding and hope around the world. We focus on all that Henry was able to accomplish through his amazing courage and the tremendous support he received from all of you.

But there is another aspect of Henry's life that is too easy to

overlook in our grief.
For too many people, growing up means slowly trading in the things that give us joy for the things that pay the mortgage, if we are lucky, we pursue our passions on the weekend after we get caught up on the laundry. We turn away from the things that delight, because they are dangerous, impractical, frivolous, or bad for your cholesterol.

Adults, for instance, will tell you that you should NEVER cut watermelon with a Samurai sword: it's incredibly dangerous, and it makes a terrible mess on the pool deck.

Henry knew that watermelon sliced with a sword tastes sweeter, and MAN do the pieces fly.[ix]

Adults know that eating out in a restaurant should be a rare treat. It's expensive and often fattening; probably it's a good idea to get the salad dressing on the side.

Henry realized that eating out was almost as much fun as room service. And that if you skipped the main entree and ordered five appetizers instead, the server would look at you funny but they'd still bring the food. And you would get the best of everything - with no vegetables.

Adults will tell you that you need to invest ten percent of your pretax income into a 401K for retirement and that blue chips are a good hedge against inflation. Henry never worried about money. He focused on investments of entirely different sort. He cultivated friendships with everyone he met. If you ever spent five minutes waiting for a bus with Henry, you got to hear one of his stories and share a piece of his life. It didn't matter if he'd never seen you before, Henry would tell you about living with AIDS, the new medications he was taking, or how his sisters used to beat on him when he was too little to fight back. Henry just loved being with people even more than he loved mozzarella sticks.

Today we are able to see the dividends that Henry's investments paid. He lived and died surrounded by people who loved and admired him.

It is tragic that Henry's life was cut short. But while he was with us, Henry was like Peter Pan- he had magic."

When Jennifer finished, Diana took the podium. Diana who is more like Joan is also a more pragmatic and practical speaker than Jennifer. She was brief. Diana spoke about the visits she shared with her brother when he came to see her in Maine on college visits where he would hide in her back yard until she came home from a late class and then jump out to successfully scare her. Diana told stories about Henry's love of lobster and the times he would indulge himself and his friends with more lobsters than should ever be eaten in a single sitting. Diana too is a moving speaker who delivered a heartfelt message in a difficult time.

After Jennifer and Diana delivered their eulogies, Howard asked to speak. Howard is the third brother in my family of five boys. I was the oldest. Howard, like Jennifer and Diana, is a born talented speaker, and like the girls, Howard's eulogy did justice to Henry's memory.

"Words can never convey adequately the sorrow, sense of shared loss or desire to comfort that we all feel on Henry's death. So beyond saying that we are all so sorry and that you have our love, I would conclude. But Henry, and you Hank, Joan, Jennifer and Diana deserve so much more.

You all have responded with amazing spirit to unbelievable adversity. Dealt the most difficult hand, Henry lived his life beautifully. There is a grace under fire that marks the strong, and he so clearly had it. Facing life with humor and purpose, he made a difference for all of us and in doing so triumphed in more ways than anyone I know. We should be thankful to have had him so long. Heaven now has a special child.

And whatever Henry's struggles and pain, he never lacked for love. His grace was born of his family; and for that and for all of you we are thankful. You are the well Henry went to when he needed strength. Your struggles and triumphs forged a

special family. Watching you all support and respect each other has been both awesome and inspiring. The marks he made on you, and you on each other, ripple outward. Thank you, and trust us that despite what you may feel right now, it is not over. The good parts, they just carry on.

So please know that while we are incredibly sad, we are also very proud of Henry and of each of you. You have our sympathy and of course our love. "

At least three TV stations covered the news of Henry's death and were present at his funeral. The community of Cooperstown turned out in large numbers. Many, many of our friends were there. The weather was beautiful, the sky was blue, and the air was cool. The church was packed. The gathering was hushed and everyone could hear Victoria sobbing in my arms as we began the service. She missed Henry very much.

Unlike her brother Zack, who was still too young to understand, and wanted to try to wake him to see if Henry was really dead, Victoria did understand the concept of forever.

At the cemetery, the service was brief. The Scouts gave Henry a final Salute. Michael Henrici folded the flag that draped Henry's oak coffin and gave the flag to Joan. In the distance, a lone bagpiper played taps. That brought on the tears again. After taps, Henry's mountain climbing buddies gave him a final belay as four rope teams lowered his casket into the grave. I don't think there was a dry eye anywhere, but I certainly couldn't tell. I was crying.

Joan and I returned home to hundreds of cards, letters, and more food and flowers than you can imagine. Our daughters both stayed with us for the next few days.

Joan and I put a candle on his grave every night for weeks. We will miss him forever.

But, as Henry told us in the E.R., we will be OK.

Epilogue

One day nearly three weeks after Henry's death, Joan was walking through the tunnel that connects the main building at Bassett Healthcare to the laboratory where she worked. She passed Dr. Walter Franck who was a physician colleague at Bassett and an acquaintance whom we knew from our church. As he approached Joan from the opposite direction, he asked her,

"How are you?"

Joan, busy at her work and on her way to her routinely hectic day trying to fill the hours with activity replied as she always did.

"Fine, how are you?"

"No," Dr. Franck stopped walking and asked, "Joan, how are you and Hank, really?"

Joan paused in the empty corridor and tears welled in her eyes. "We are ok. We are at least as well as we can be. We are still not sleeping and we miss him terribly." Joan told truthfully.

Walter paused and after a few second said,

"Joan, we are all so sorry for your loss and our thoughts and prayers are with you both. You and Hank have been given a terrible burden to carry. The unexpected, premature, and tragic loss of your son is so unfair. I am sure that it seems an impossible and it is almost too much to have to endure. It is almost like a huge rock that is to large to carry has been place unwillingly and uncomfortably on your shoulders." He paused again and then continued;

"However, you must carry it. You have no choice. You and Hank will carry this burden not just today, but each of you get to carry it every day for the rest of your life. You may never place the burden down. You may never forget it. You may never share it. It is yours and Hank's alone. But you must trust that, although today it seems heavy and impossible, in time you will develop the strength to carry this impossible burden. You will develop new muscles and ways of bearing the loss of your son so that some day the burden of his death will not be so overwhelming. One day things will seem normal again. And finally, I think that you may come to understand that with the burden of this great loss comes the joy and wonderful memories of the love and life of the special person Henry was and the special times you all shared. Without the burden of those memories, there would be no joy of the love and the special things your family shared."

Joan was crying now. But Walt continued,

"It is terrible what you all have endured, but it is wonderful what you will get to take in love and memory of what you all have done and shared with us all. I want to thank you for sharing Henry's life with us all and let you know that our thoughts and prayers are with you."

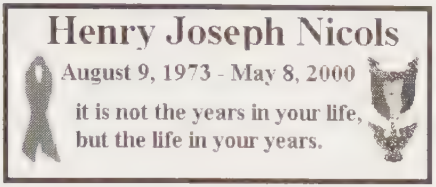
Joan was speechless. Not only was there nothing to say, she would have been unable to speak if there had been. Silently, drying her tears with the always present tissues that she now carried, she returned to work.

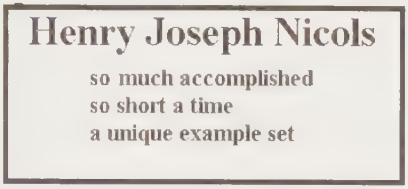
Dr. Franck's unsolicited perspective greatly touched Joan so much so that when she shared it with me later that evening, we both cried. Walt had eloquently described what we both knew in our hearts to be correct. It was not until years later that we were able to thank him for his insight and compassion. In the years that would follow I often used that analogy to describe how we came to think of our loss. I have often shared the perspective that with great grief there is also great joy.

It helped us to cope, in a time when we needed help coping.

Physical Memorials to Henry

At his grave: Henry is buried in the Riverside Cemetery on the north east side of the village of Cooperstown. His gravestone looks like this:





At Henry's grave there is a stone bench nearby where people can sit when they visit. Joan and I visit after mass on Sunday. Others stop by regularly as well. Every year on his birthday, Nick Sellars, who was a school mate and Boy Scout stops to visit, remember and celebrate Henry's Birthday. Nick always leaves a reminder of the time he and Henry spent together.

At his Scout Camp: Ten miles south of the Village of Cooperstown at Henderson Scout Reservation is a flag pole. At the base of that flag pole is a stone cairn. Stone cairns were used in the desert and above the tree line when often there was no other way to mark a trail. Travelers passing by who wished to return or to show others the way would often pile stones to mark the trail. Stone cairns are effective, easy to build and last for thousands of years.

Henry was a Cub Scout, a Boy Scout, and an Eagle Scout. He worked at Crumhorn Scout Camp on the waterfront and in the craft lodge. He hiked, canoed and camped across the United States and around the world, travelling as far away as Japan and Switzerland. He enjoyed outdoor activities, from SCUBA diving to mountain climbing. His favorite mountains were Mt. Rainier in the State of Washington and the Matterhorn in Switzerland. Henry often used cairns to find his way.

Henry was a Hemophiliac. Henry had AIDS. He was the first person in the world who planned and told his school and community that he had AIDS. Henry's Eagle Scout project was about AIDS education. He traveled around the United States and across the world setting up AIDS support groups and showing the myths and the realities of AIDS. Like a stone cairn, Henry showed the way.

Like a cairn, he showed us the way during a difficult journey. It is our responsibility as Scouts to continue the tradition, to show the way that others might follow!

At the entrance to Crumhorn Mountain Camp are some of the stones that Henry collected in his travels. Stones there are from the Grand Canyon, Bryce & Zion Parks in Utah, the Matterhorn in Switzerland, and Mt. Rainier in Washington, from the Appalachian Trail, and from the Summit of Baxter Peak in Maine. There is coral from the beaches of Florida and the beaches of the Pacific Northwest, and from beaches around the world. People are invited to leave a small stone as well. The stones left could be from a high peak, a private place or a favorite retreat. People are asked to please keep the stone smaller than a baseball and to register the stone in the logbook at Henry's Cairn.

At his school: The entrance to the Cooperstown High School is marked with a memorial garden dedicated to Henry and marked with a wall plaque that depicts the large and distinctive mountain profile of Mount Katahdin. The plaque was designed by Scoutmaster Tony Scalici and placed by the Scouts of Troop 1254 as a tribute to the work Henry had done in AIDS education and to the support the school and Cooperstown community had provided to him. The memorial garden at the school is maintained by Joan and Ann Capozza the mother of three of our scouts, Dan, Allie and Julia who all hiked and camped with Henry in Grand Canyon, Mt. Katahdin, and the Florida Everglades.

At his church: St. Mary's, Roman Catholic Church in Cooperstown has a flagpole dedicated to Henry Nicols, who was a Parishioner at the church.

Family Update

Diana Nicols lives with her husband Mark diLorenzo and his two sons, Lee and Ethan, and their three children, Tess, Lincoln and Tara in Cooperstown, NY. Diana serves the community as the Police Chief of the Cooperstown Police Department. Diana is an adjunct instructor for the State University of New York College at Oneonta and teaches courses in Criminal Justice and Self Defense.

Jennifer Nicols Curtis, Ed. D. lives with her husband Todd Curtis and their two children, Victoria and Zachary. They live in Cortland, NY, where Jena is an assistant professor of Health Education and the Coordinator of the Human Services Program. Jennifer is an active HIV/ AIDS educator and has traveled widely both nationally and internationally to speak about important health and human issues especially related to AIDS.

Joan Nicols lives with Hank and continues her work in transfusion services in the laboratory of Bassett Healthcare in Cooperstown, NY. Joan remains active in HIV/AIDS educations and presents programs on Living with AIDS on request.

Hank Nicols, lives in Cooperstown with Joan and travels and teaches internationally for the State University of New York, College at Buffalo's Graduate Program for International Educators. Hank teaches courses in more than thirty countries around the world. He has taught in Africa, Asia, Latin America, the Middle East and Europe. He continues to be an advocate for those with HIV/AIDS and teaches compassion and emotional understanding. He remains active in the Scouting movement.

"My name is Henry Nicols and I have AIDS." March 8, 1991 – Henry Nicols

"Until today I never told anyone that I have AIDS. I never told a friend, a girlfriend or a relative. I am unwilling to remain silent any longer." – Henry Nicols

"AIDS isn't dangerous. Ignorance is." – Henry Nicols

"AIDS is not a punishment from God. There is nothing that anyone could do to deserve AIDS"." – Henry Nicols

" HIV/AIDS isn't my disease, it is our disease and until we treat it as a virus and as a disease we are not going to be able to manage this crisis." – Henry Nicols

"No one should have to live with AIDS and the fear that they will be rejected by the ones they love." - Henry Nicols

"I never really thought of myself becoming a role model. It's not something I said as a little kid –'One day, I'm going to be a role model.' It's just something that happened." - Henry Nicols

"What do you think it is like to die? We are all going to die. We just don't know when. If I stop living my life now and wait to die, I won't be living. So my plan is to live my life the best way I know how. I am not going to die today." – Henry Nicols

"My name is Henry Nicols. I do have AIDS, and you can't tell if someone has AIDS by looking! AIDS isn't a gay disease. AIDS isn't a drug addict's disease. AIDS isn't my disease. AIDS is our disease. If I am the first person you have met with AIDS you are lucky. I promise you I won't be the last." - Henry Nicols

"Skip the entrée and order the appetizers." - Henry Nicols

"Watermelon sliced with a samurai sword tastes sweeter." - Henry Nicols

"There were some red necks, but we spoke with them." - Michael "Beef" Calhoun

"It is never too late to be infected with courage." – Jennifer Nicols Curtis

"While he was with us, Henry was Peter Pan. He had the magic." – Jennifer Nicols Curtis

Figure 24 He Had The Magic.

(When asked what he wanted to do before he died.)

"I am glad you asked that. Most people think I want to go to Disneyland or something like that but that is not it. I want to run for President. I figured it out. In 2008 I will be 34 years old, but I will turn 35 during the Primary. So, in 2008, it is Henry for President!" - Henry Nicols

I asked a long time personal and family friend, Bob Hildebrand to help me by writing a "blurb" for the back cover of the book. Bob obliged and wrote this, too long for a blurb, but too good to be left out of the book, so it has become the Introduction to the Action Plan.

"Hank (the author) was my Boy Scout Patrol Leader in Troop 33, in 1964 in Hempstead, NY. Our friendship was cemented by that association with the Boy Scouts. We canoed 200 miles down the Delaware River in a most action packed and sometimes dangerous experience. We worked at Onteora Scout Reservation in Livingston Manor together and have been life long friends. His son Henry was the epitome of the Boy Scout Milieu. He was a sentinel of the overwhelming tide of what has turned out to be a worldwide catastrophe. He was also a role model for my twin sons, both Eagle Scouts and a dear friend to my daughter. Hank's father and Henry's grandfather was one of my Scout leaders who gave so much time and energy for the benefit of us snotty-nosed kids, an adult beacon in a world of 1960's adult apathy and indifference.

In the Boy Scout Movement, there is a special group of honor campers who are elected by their peers for their dedication to cheerful service to the benefit of others. This group has a tradition from the Native American Lene Lanepe or Delaware Tribe. At one time there was a young brave who volunteered to spread the word that invaders were about to attack. At personal risk, this brave traveled several hundred miles to warn neighboring families and villages that the attack was imminent. When the invaders attacked, the tribe was prepared and the invaders were repelled. For his heroism and bravery, this young brave, the son of the Chief, was honored with the institution of the "Brotherhood of Cheerful Service." The parallel to Henry's life is obvious.

What courage it must have taken in 1990 to first stand up in front of his high school and say, "I have AIDS." In essence admitting to a disease that was at that time was attributed to IV drug users and homosexuals. This courage, this strength of character is the hallmark of heroes. This is a young man who went to the front of his class and said, "Look out, there's danger ahead." Not a message we like to hear. He certainly was from the tradition of the prophets as he proclaimed a message of truth, and a message of healing.

Henry came to stay with my family for a short while to address an AIDS conference in Melbourne, Florida, he was impulsive and edgy, yet when he got up to speak, he was pure "Henry". His words were of healing and consolidation, he was exhausted at the end.

I can say for my wife and children and the scouts that have known him that Henry gave us a message of warning, a message of hope and a message of love, and while we will always miss him, we will never forget him."

Robert Hildebrand - Boy Scout, Scoutmaster,
Silver Beaver and long time Nicols Family friend!

And, so it is with Henry's Legacy. It is a story that will survive him, but the story of Henry's life is not about the events of his life but what he did in spite of the things that happened to him. Henry learned that normal is what you have even when it is an extraordinary challenge. A Hemophiliac from birth, Henry never believed that he was handicapped. Hemophilia was the reality of his life.

Exposed to HIV / AIDS before the world even knew the word, Henry knew that he had to live his life, and not prepare to meet his death.

In a time when science and logic were silenced and fear and misunderstanding ruled, Henry refused to go with the majority opinion and direction. When no one else dared say it Henry held a press conference to announce:

"My name is Henry Nicols and I have AIDS."

Unfortunately you can't vote for Henry for President but here is what you can do.

1. **Refuse to be silent** in the face of discrimination. Discrimination against anyone for fear, sexual orientation, race, or creed diminishes each of us and allows injustice to be perpetrated.

2. **Speak** for those who can not speak for themselves. Together we each have a responsibility to ensure that everyone is heard. Not just those with loud voices.

3. **Participate**. The only thing necessary for the success of evil or even the success of mediocrity is for good people to do nothing. Do something. Vote.

4. **Teach courage**. Henry is a model for what can be done with courage in the face of overwhelming circumstance.

5. **Teach hope** especially where there is hopelessness.

6. Finally, do something to **Change the World**. The only people who ever change the world for the better are those who try. A little at a time will do it.

And in the final analysis Henry's legacy is not about him, or his family, or hemophilia or AIDS. Henry's legacy is about changing ourselves and then the world by the way we live our lives, whatever the circumstances, whatever the challenges.

Now let us go and do it.

That is Henry's legacy!

Additional Resources

There are many sources for additional information about Hemophilia or HIV / AIDS and about the struggle during the early days of the epidemic. I would recommend these few.

Books:

Journey (1984) by Robert K. and Suzanne Massie

And The Band Played On (1987) by Randy Shilts

Living Proof: Courage In The Face Of AIDS 1994 by Carolyn Jones

Internet Resources:

AIDS.Org
http://www.aids.org/

United Nations Program on HIV/AIDS
http://www.unaids.org/en/

United States Department: Health and Human Services
http://www.aidsinfo.nih.gov/

National Hemophilia Foundation
http://www.hemophilia.org/

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[1] *A Punnett Square shows the determination of gender by the contribution of X & Y chromosomes, for example, in the Punnett square below, the mother, (XX,) on the top row, contributes either of her X chromosomes to her child, and the father, (XY,) represented on the left, contributes either an X or a Y. In cases where the father contributes an X chromosome, the child is female. If the father contributes a Y chromosome, the child would be a male. XX = female XY= male.*

Genetic Determination Of The Sex Of A Child		
	X	*X*
X	*XX*	*XX*
Y	*XY*	*XY*

[2] *Classical Hemophiliacs are missing the eighth protein, and because number VIII fails to act, the rest of the clotting factors are unable to interact as well, and the result is that the blood does not clot. This specific clotting factor "VIII" is "carried" on one of the X chromosomes. Females have two X chromosomes, and therefore a women missing one X with clotting ability would still have a spare X and would often have about half normal clotting ability. Males only get one X chromosome, and missing a normal one would mean that they and their blood would not be able to clot.*

Genetic Transmission Of Hemophilia		
	X	***X´***
X	*XX*	*X* ***X´***
Y	*XY*	***X´Y***

In the transmission of Hemophilia, the mother "carries" the genetic marker for Hemophilia on an X chromosome, shown in the tables as ***X´****. She then "donates' that genetic code to 50% of her children. Jennifer and Diana had each inherited an X from Hank and an* ***X´*** *from Joan. They had a spare X chromosome with clotting ability. Henry inherited a Y chromosome from Hank and an* ***X´*** *chromosome from Joan. His only X chromosome carried the marker*

for Hemophilia and, not having a spare X chromosome like his sisters, Henry was a Hemophiliac.

The transfusion or infusion process began a simple but exact step by step procedure.

1. *Interrupt Henry from play, sleep, or eating. (which is what he was most often doing prior to his transfusions)*
2. *Determine the number of bags of Cryoprecipitate to raise his clotting level to a normal range of 50 - 100% (depending on Henry's weight and the seriousness of his injury)*
3. *Collect the bags from the freezer*
4. *Defrost the frozen Cryo in a warm water bath.*
5. *Assemble the infusion kit from the syringe, needle, and tubing.*
6. *Add saline to the bags to suspend the cryo.*
7. *Pool the multiple bags of Cryo each containing 15-30 cc of fluid into a single bag containing 150 - 300 cc of fluid.*
8. *Use the alcohol pad to clean the site of the venipuncture*
9. *Use the tourniquet to raise the vein*
10. *Use the needle to enter a vein*
11. *Release the tourniquet*
12. *Draw Cryo into the syringe*
13. *Clamp off the bag of fluid*
14. *Slowly inject the Cryo into the vein*
15. *Clamp off the tube leading to the vein*
16. *Release the clamp on the Cryo bag and refill the syringe repeating as necessary.*
17. *When all the Cryo has been transfused from the bag into Henry, withdraw the needle and apply pressure and bandage to the venipuncture site.*
18. *Send Henry back to play, sleep or eat.*

Dr. Robert Gallo of the National Cancer Institute and French medical researcher Dr. Luc Montagnier of the Pasteur institute eventually shared the claim as the discovers of the Human Immunodeficiency Virus.

Joan's younger sister Kathleen and my younger brother Steven who both moved to Cooperstown to support Joan in our pending crisis ended up falling in love and getting married. I like to drive my sister in law Kathleen crazy by saying that when she saw what a good husband Joan had gotten she wanted a piece of the action so she married my little brother. I am almost certain that their marriage

makes Kathleen my Sister-in-law-Sister-in-law, and Steven my Brother-Brother-in-law. Come to think of it, it drives me crazy too!

[iv] *"Do not go gentle into that good night, ...rage rage against the dying of the light." from the poem by Dylan Thomas*

[v] *"Eagle Scout, The Henry Nicols Story" was originally a Documentary by: Michael Ryan, Ellen Stokes, Debora Gilbert; Photography: Robert Aches, Lou Monig, Kathy Corley, Todd Curtis, Erik Torbeck; Sound: Paul Bang, Cathy Corley, Michael Ryan, Ellen Stokes; Edited by: Bill Fogarty, Karen Heyson, Ted Winterburn Special Thanks to: The Nicols Family , Henry, Joan, Hank, Jen, Todd, Diana, and all their grandparents, uncles, aunts & cousins; Special thanks to: Bruce Reinholdt, Paul Bedworth, Dr. Gerry Bers, Rich Maul, and members of Boy Scout Troop 1254, Dr. Douglas Bradshaw and the Cooperstown Schools, Chris Van Cour, Mandy Moorecraft, Ken Screven, WRGB-TV Schenectady, The People of Cooperstown, The School districts of Oneonta and Milford, NY and Sheila Nevins, Sal's Pizza, The Tunnicliff, Oneonta karate; Still Photography Edited by; Steve Freeman; Edited at: Gilbert Communications, St. Louis; Edit Decisions, Ltd; NY; Produced by Eagle Scout Partnership in collaboration with Scouts Honor Productions; Peach Production Co, PO Box 15601, St Louis, Mo 63105; MCMCXIV*

[vi] *The HBO documentary, "Eagle Scout: the Henry Nicols Story" was Produced by: Michael Ryan, Deborah Gilbert. Ellen Stokes, Cinematographers: Robert Achs, Lou Monnig, Kathy Corley, Todd Curtis, Erik Torbeck. Music & Sound Design: Richard Fiocca, Sound: Paul Bang, Kathy Corle, Michael Ryan, Ellen Stokes, On Line Editor: Richard Rachback, Sound Mixer: John Wiggins, Edited by: Max Weissman, Associate Producer: Jonathan Moss, Executive Producer: Sheila Nevins*

[vii] *Henry had two samurai swords in his collection. After his death Joan and I gave one to Erik Torbeck the other was given to his "twin brother" Chris Vancour.*

Made in the USA
Middletown, DE
30 August 2015

A compelling story I couldn't put down. I knew Henry was special the day he came into my studio. There was a swagger to his pose, a confidence; he was a boy becoming a man. My heart was touched. He has shown us the way. His story is one of courage, a young man who overcame tragedy with grace. He shows us how to cherish our families, how to love one another. Henry told us "to live life the best way we know how," this book shows us how he overcame so many challenges to find joy and love. *Carolyn Jones, Author: "Living Proof: Courage in the Face of AIDS."*

When I traveled to Cooperstown in 1991 to interview Henry Nicols and his family for a magazine story, I knew instantly that a larger medium was called for. When I returned home and told my wife, Debbie, that I wanted to make a documentary film about the Nicols, she agreed on the spot. We believed it was important to help Henry and his family reach a wider audience. The story of a young man struggling with a life threatening and stigmatizing disease, stepping up to the plate to spend what little time he had left to help others is as heartrending as it is inspiring. "Henry for President," tells the story from a father's perspective underlining the importance of seizing the moment to spend time right now with those we love. *--Michael Ryan, Producer, Director of "Eagle Scout, The Story of Henry Nicols"*

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